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ABSTRACT

This report describes the proceedings of a three-day workshop on community-based rehabilitation (CBR) models and training in India. The workshop included 72 professionals from India, Sri Lanka, Nepal, Canada, and the United Kingdom. Sessions and papers from the workshop are summarized and address the following topics: (1) a training module for the multipurpose rehabilitation worker; (2) the Rehabilitation Council of India's approach toward CBR; (3) the role of the United Nations Children's Education Fund; (4) whether CBR models are viable for India; (5) the outcome of a needs assessment survey of 1,683 individuals with disabilities; (6) prevention of low birth weight; (7) empowerment of individuals with mental retardation; (8) factors for success in rehabilitation; (9) the importance of worker's attitudes in CBR; (10) curriculum for personnel training in CBR; (11) training and evaluation in CBR; (12) curriculum for training for working with specific disabilities; (13) employing people with disabilities; (14) proposed policies and development of a CBR program for persons with disabilities; (15) CBR in practice in India; (16) the CBR linkage model of early intervention; (17) a CBR fact sheet; and (18) self help groups for adults with disability in CBR programs. (CR)

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PROCEEDINGS OF THE WORKSHOP ON "CBR MODELS AND TRAINING VIABLE FOR INDIA"

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The Spastics Society of Tamil Nadu

Rehabilitation Council of India, New Delhi

UNICEF, Chennai

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THE SPASTICS SOCIETY OF TAMIL NADU
(SPASTN)

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WORKSHOP ON CBR MODEL AND TRAINING VIABLE FOR INDIA

Subject	: Community Based Rehabilitation
Date	: 3rd, 4th and 5th March 1997
Venue	: The Spastics Society of Tamilnadu, Chennai.
Organisors	: The Spastics Society of Tamilnadu, Chennai. (SPASTN)
Sponsors	: Rehabilitation Council of India - New Delhi and UNICEF - Chennai.
Organising Committee	: Mrs. Seetha Muthiah - President Mrs. Aloka Guha - Director
Scientific Session	: Ms. Nalini James Mrs. Aruna Leonard Mrs. Sheba Thomas
Transportation	: Ms. Astrid Udo Mr. Richard Maburi Mr. Soundararaja
Hospitality	: Mrs. Lalitha Muralidharan Ms. Christinal
Physical Arrangements	: Mr. E.A. Parimelazhagan Mr. Ganesh Mr. Jayaraj Mr. Manohar Ms. Mercy Hema Mr. M.A. Thibble

Overall Supervisors	: Mrs. Lakshmi R. Sarma Ms. Shalini Nair Ms. Rajee Mrs. Viji Mr. Ilamathy	
Stalls	: Mr. Jyothilingam Ms. S. Jayashree Mrs. K. Jayashree Mr. Chandrasekar Mr. Shanmuga Sundaram	
Support Staff	: Mrs. Vasuki Mrs. Valarmathy Mrs. Kumari Mrs. Padmini	
Countries Represented	: Canada, Nepal, Sri Lanka, Germany, United Kingdom and India	
Total Number of Participants	: 72	
State-wise Breakdown of Indian delegates	: Andhra Pradesh	– 4
	Gujarat	– 2
	Karnataka	– 4
	Kerala	– 5
	Maharashtra	– 2
	New Delhi	– 5
	Tamilnadu	– 36
	Uttar Pradesh	– 1
	West Bengal	– 1
International delegates	: 12	

Proceedings of the Workshop
On
"CBR Models and Training Viable for India"
on 3rd,4th and 5th March 1997.

A three day workshop was organised in Chennai by The Spastics Society of Tamil Nadu and Co-sponsored by the Rehabilitation Council of India, New Delhi and UNICEF, Chennai . A total of 72 professionals participated from all over India, Srilanka, Nepal, Canada and the United Kingdom.

DAY ONE 03.03.97

The workshop began with a 20 minute session on Pranic Meditation led by Mrs. Ramani Joseph from the Pranic Healing Foundation, Chennai. Later, all the delegates admitted to the refreshing and soothing quality of the meditation that stayed with them all day.

The inaugural function was presided over by Dr.(Major) Raja, Vice Chancellor, Dr.M.G.R. University, Chennai and Dr.B.P. Yadav, Chairman, Rehabilitation Council of India, New Delhi. Mrs. Seetha Muthiah, President, The Spastics Society of Tamil Nadu welcomed the gathering. Dr. B.P.Yadav then spoke on the need for strengthening training programmes for CBR Personnel.

The participants were divided into four heterogenous groups for the entire period of the workshop. The first day was divided into 3 scientific sessions.

SESSION - I

SHARING OF EXPERIENCES

This session was chaired by Dr. Vijayaraghavan, Director of Public Health, Chennai and Co-chaired by Dr.Tara, Director, Schizophrenia Association Research Foundation, Chennai. The presenters were Dr.R.K. Srivastava, Director, Safdarjung Hospital, New Delhi and Dr.H.C.Goel, Head, Department of Rehabilitation, Safdarjung Hospital, New Delhi.

Dr.Vijayaraghavan, in his addresss, said that The Department of Public Health and Preventive Medicine had been associated in various capacities with The Spastics Society of Tamil Nadu for the past 3 years. It is estimated that there are 5.5 lakh children with disabilities below the age of 6 years. This department has now taken on the task of identifying people affected by leprosy, and they hope to eradicate leprosy from the state of Tamil Nadu by the next 5 years.This department is now ready to take on the task of identifying children and people with disabilities. He was of the view that a health worker, could not be spared for 4 months to be trained in issues relating to disability, but that shorter modules of 3 to 4 weeks would be a viable option.

Dr.Tara, in her address said that mental health problems are now recognised and included as a disability as indicated in the legislation passed in January 1996. She emphasised that her organisation would like to be involved in any training programme.

SPEAKER : Dr.R.K.Srivastava,Director, Safdarjung Hospital,New Delhi.

TOPIC : TRAINING MODULE OF MULTIPURPOSE REHABILITATION WORKER (MRW)

A brief summary:

- CBR is a strategy to develop the entire community where people with disabilities are seen as an integral part of the Community. Every community has its own assets which are not fully accessible to people with disabilities. The World Health Organisation has recognized 23 needs (apart from basic needs) which are not met by people with disabilities. There has to be some one to mobilise the community and to see that these needs are met.
- The MRW could be the person to do this. He/she is a core functionary in a CBR programme.
- A MRW will be a member of the primary health care team, with skills and knowledge necessary for the rehabilitation of the disabled in the community.
- Presently there are 6 to 7 centres offering this training programme in the country.
- Tasks to be performed by a MRW are :
  - Facilitatory :
    - transfer of knowledge and skills necessary for the rehabilitation of the person with disability
      - to the person,
      - family and community.
    - To form advocacy groups.
  - Managerial :
    - compilation of data,
    - keeping records and
    - evaluating the programme.
  - Educational :
    - training of community rehabilitation worker (CRW)
    - creating awareness among opinion makers of the community.
- The method of teaching should be
  - Interactive
  - Encourage problem solving
  - Flexible
  - Repetitive
  - Modular
- The duration of training is for 1 1/2 years, divided into 4 modules.
  - Module-I : Includes theory on loco motor, visual & hearing impairments, epilepsy, cerebral palsy, leprosy,mental health problems.
  - Module-II : Networking with other agencies.

- Module-III : Occupational therapy, and Speech therapy.
- Module-IV : To be chosen by the trainees where they need additional inputs.

- Criteria for selection:
  - minimum age : 18 years
  - should have passed : Standard 12
  - should be able to read and write English plus any one regional language
- Staff required:
  - 3 full time teachers
  - 2 part time teachers
- The emphasis will be more on skill training rather than theory.
- There will be an evaluation at the end of each module based on pre- set questions that will be given to the trainees at the beginning of the session. For module IV, questions will be decided on jointly by the teacher and trainee.
- The certificate will be awarded by The Rehabilitation Council of India, New Delhi.

An Important Point to consider:

Dr. Srivastava urged Tamil Nadu to take up this training earnestly.

SPEAKER : Dr.H.C.Goel, Head, Department of Rehabilitation, Safdarjung Hospital, New Delhi.

TOPIC : APPROACH OF THE REHABILITATION COUNCIL OF INDIA TOWARDS COMMUNITY BASED REHABILITATION, (CBR).

A brief summary:

The Rehabilitation Council of India, New Delhi, advocates a broad definition of CBR that encompasses:

- Maximisation of physical and mental abilities.
- Achievement of full social integration.
- Advocate the rights of persons with disabilities.
- Actively lobby with the government to empower the community.
- Provide a comprehensive rehabilitation program.

There are different approaches to CBR. Some of which are :

- Programs in rural areas
- Out reach programs
- Distribution of aids and appliances
- Organising camps
- Community development program.

The Rehabilitation Council of India advocates the community development approach.

Role of the Rehabilitation Council of India in CBR:

- The Rehabilitation Council of India has a very positive approach to CBR.
- It has undertaken several programs to sensitise senior professionals in CBR in different parts of the country.
- It is actively involved in the devlopment of human resources.
- As a statutory body it standardizes curriculum for rehabilitation personnel. Some of the types of curriculum developed so far are:
  - — training of CBR workers
  - — training of multipurpose rehabilitation workers (MRW)
  - — training of master trainers for CBR
  - — training of CBR managers
  - — inservice training on CBR in health care programs.
- It evaluates and monitors training programs across the country.
- It is actively involved in the development of training materials.
- It networks with Governmental and non-governmental organisations.

SESSION II

SHARING OF EXPERIENCES - "THE DONOR'S ROLE"

This session was chaired by Dr. Jeyachandran, Principal, Bala Vihar, Chennai and Co-chaired by Mrs. Gool. R.Plumber, Association for the Welfare of the Mentally Handicapped, Hyderabad.

SPEAKER : Ms. Elke Krause, United Nations Children's Education Fund (UNICEF), Chennai

TOPIC : "THE DONOR'S ROLE"

A brief summary:

- UNICEF supports the development of models that can be replicated.
- They fund existing projects to strengthen the capacity of personnel like village health nurses, anganwadi workers and supervisors.
- UNICEF has learnt much about the needs of the disabled and the need for CBR from its interactions with The Spastics Society of Tamil Nadu and Child Development Centre, Trivandrum.
- They now fund programs that address the needs of the community.
- Funding is based on the needs of the program and is faded out as the government takes over.
- An important role that UNICEF plays is in bringing the government and non-governmental organisations together, which she feels is a challenging role.

The spdnsors

Registration Counter

The Inauguration -
Chief Guest
Dr. (Major) Raja
Vice Chancellor -
Dr. M.G.R. University -
Chennai.
Guest of Honour
Dr. B.P. Yadav
Chairman - Rehabilitation
Council of India - New Delhi
Host : Mrs. Seetha Muthiah
President - SPASTN

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SPEAKER : Mr. K.R. Rajendra, Action-Aid, Bangalore

TOPIC : "THE DONOR'S ROLE "

- Action Aid funds programs that are involved in :
  - — eradication of poverty
  - — issues relating to women and disability
  - — integrated rural development program.
- About 10% of their financial outlay is for rehabilitation of persons with disability.
- The overall objective of Action- Aid is to improve the quality of life and enable people to live in dignity. It also aims to promote and upgrade the field of rehabilitation.
- They fund centre based as well as CBR programs.
- Action-Aid has recognised the need for :
  - — Dissemination of learning : through their news letter ~ Action Aid Disability News.
  - — Training : by creating manpower development centres.
  - — Capacity building : training managers and planners.
  - — Research : to develop appropriate technology and methodology.
  - — Vocational rehabilitation : which they consider to be the toughest job.

LUNCH BREAK

The afternoon session began with an exercise that was designed to break the post lunch drowsiness. All the participants were asked to write down the first word that came to their mind in association with the words :

C B R

Training

This session was moderated by Ms. Elke Krause, UNICEF, Chennai and Mr. Simon- Save the Children Fund, Chennai.

The words given by the participants are presented here, to give an overview of how professionals perceive CBR and Training.

CBR

- — Empowerment
- — Individual
- — Demystification
- — Empowerment of person's with disability
- — Community
- — Community Participation Problem
- — CBR enables total rehabilitation
- — Coverage

- People
- Home Based Program
- It is very much necessary in rural areas
- Cars, Buses, Roads (CBR)
- Not in Europe
- Boon to developing countries
- Confusion
- Disabled
- It is used disabled child
- Hopefully
- Sustainability
- Good service for disabled
- Developing to helping villages
- It is very useful for all people
- Habilitate first
- Basic intervention facilities at community nutrition centre
- Local resource
- Involuntary people
- Community involvement
- Community need
- Comprehensive approach essential
- Community participation
- Networking
- Inclusion
- Good
- Needed ?
- Funds
- Involvement
- Disability oriented
- Resource
- People's participation
- Organising
- Rehabilitation
- Client- centered
- Prevention and early detection essential

TRAINING

- Trained manpower
- Need based
- Reaching out

- CBR training is more important in the disability members
- Training the disabled, mothers and grassroots level health and welfare functionaries
- Enabling
- Participation
- Must be accurate and careful
- Manpower development
- Opportunities
- Training people
- From grassroots level
- Duration
- Need based
- Client oriented
- Skills
- Training time is short here
- Good modules gathered here
- Both category
- Must
- Attitudes
- Grassroot level training
- Training need identification
- Adaptable
- What ?
- Project
- TA and DA
- Appropriate and relevant
- Training mothers and familiy
- Skill promotion
- Appropriate
- Must be given to basic level program
- Good
- Flexibility
- Training of persons with disability
- Participatory
- Facilitator
- Development
- CBR managers training
- Manpower
- Demystification

— Participatory methodology
— Empowerment
— Feasibility
— Equip efficient implementation rehabilitation
— Corruption
— Informal need based
— Help

SESSION III

SHARING OF EXPERIENCES "CBR MODELS VIABLE FOR INDIA ".

This session was chaired by Dr.B.P.Yadav, Chairman, Rehabilitation Council of India, New Delhi and Dr. Bhushan Punani, Blind Men's Association, Ahmedabad; and Co-chaired by Dr. Padmanabhan, Deputy Director, Department of Public Health and Preventive Medicine, Chennai.

The presenters were :

- Mr. K.R. Rajendra, Sri Ramana Maharishi Academy for the Blind; Action Aid India, Bangalore.
- Dr. M.K.C. Nair
  SAT Hospital, Trivandrum
- Dr. Narendra Bedi
  Young India Project, Andhra Pradesh
- Ms. Nandini Rawal
  Blind Men's Association, Ahmedabad
- Mrs. Ruma Banerjee
  Seva-In-Action, Bangalore
- Mrs. Aloka Guha
  The Spastics Society of Tamil Nadu, Chennai

There was a special persentation by Mr. John Patterson, International Centre for the Advancement of Community Based Rehabilitation(ICACBR), Queen's University, Canada.

In the post - tea session, a group interactive session was organised. Each group discussed the STRENGTHS, COMMONALITIES, HUMAN RESOURCE DEVELOPMENT IMPLICATION and OPPORTUNITIES of all the six CBR models presented. This session was chaired by Mr. Krishna Prasad, Director, Hospital and Rehabilitation for Disabled Children, Kathmandu, Nepal; and co -chaired by Mr.John Patterson, International Centre for the Advancement of Community Based Rehabilitation, Queen's University, Canada.

The presentation of the four groups were as follows:

GROUP ONE : STRENGTHS :

- Creating awareness
- Involving the government
- Training of personnel has been culturally appropriate.
- Empowerment of persons with disability.

- Networking and sharing of information
- Mobilising the community and its resources.

GROUP TWO: COMMONALITIES

- Creating awareness
- Screening for early detection
- Early intervention
- Development of human resources
- A system to deliver services
- Empowerment of the community.
- Tapping resources outside the community
- A well defined structure
- Emphasis on work at the grass roots level
- Successful programs?

GROUP THREE : HRD IMPLICATIONS

- Need training for:
  - — CBR worker
  - — Coordinator
  - — Manager
- Training should include:
  - — CBR
  - — low cost aids
  - — Inclusive education
  - — Measures to bring about attitudinal change of people in the community towards persons with disability.

GROUP FOUR : OPPORTUNITIES

- Empower persons with disability
- Build on existing capacities
- Integrate children with disabilities in the regular schools in the villages
- Training of different cadres from Health, Women and Child Development, Welfare, Nutrition and Education
- Mobilise resources
- Participation of community members in the program

Following this a synthesis report was presented by Ms. Nalini James and Ms. Aruna Leonard from The Spastics Society of Tamil Nadu, Chennai.

This brought the proceedings of day one to an end.

PAPER ONE

PRESENTER	: Mr.K.R.Rajendra
NAME OF AGENCY	: Sri Ramana Maharishi Academy for the Blind, Bangalore
NAME OF THE PROJECT	: Sourabha
LOCATION	: Kanakapura, a rural district near Bangalore
YEAR OF LAUNCHING	: 1990
NUMBER ON TEAM	: 5 members
TARGET	: 147 villages
TOTAL POPULATION	: 1.5 lakhs
FUNDING AGENCY	: Action Aid

EVOLUTION OF THE PROGRAMME :

1991 : Training of CBR workers :

Young men and women who had finished Std X and in the age group of 20 to 25 years were selected from the villages. Care was taken to maintain the gender ratio of the workers: 50% of the trainees were men and 50% were women. They were trained for one year. During this period, they were taught theory by professionals for one day every week; and the remaining 6 days was practical work. Each trainee was assigned 6 to 8 villages to deal with all disabilities.

1992 : Survey

A door-to-door survey was done to identify persons with disabilities in the age group of birth to 45 years and to assess their needs. A total of 1683 persons were identified and a programme was planned and implemented to meet the needs of these persons.

1993 : Programme evaluation :

The programme was evaluated from the perspective of

- the person with the disability
- the family of the disabled person
- the community.

The evaluation revealed :

- Medical rehabilitation was successful
- Community participation was lacking
- The satisfaction of persons with severe and profound disability towards the programme was lower.

1995 : LONG TERM PLAN :

These plans addressed the needs of persons with severe and profound disability.

1996 : WITHDRAWAL PLAN :

To handover the programme to:

- the person with disability
- the family of the disabled person
- the community

SOME IMPORTANT LESSONS LEARNED :

Plan in such a way that the programme will be sustainable. A few ways to ensure this are:

- formation of local groups
- motivate existing groups [empower these groups to take up issues relating to disability]
- enhance community participation
- network with government and NGO's
- transfer skills to local groups
  - — financial skills
  - — managerial skills
  - — technical skills
- treat persons with severe disability as a priority
- strengthen income generating programmes.
- design and implement withdrawal plan

Key factors for success :

- Involvement of management in grass roots workers
- Involvement of the person with disability, the family and the community
- Well-defined structure-a bottom-up planning approach.
- Training inputs to project team(inservice and external)
- Long term support from funding agencies(technical and financial support)

PAPER TWO

PRESENTER	: Dr. M.K.C.Nair, M.D, DCH, FIAP, M.MED.Sc., Director, Child Development Centre, Medical College Campus, Thiruvanthapuram.
NAME OF THE AGENCY	: SAT Hospital, Thiruvanthapuram
NAME OF THE PROJECT	: Prevention of childhood disability, Kerala model
LOCATION	: Four Integrated Child Development Scheme (ICDS) blocks-Chavara, Madapally, Koduvally, Sasthamkotta

ABOUT THE PROGRAMME :

This centre has found low birth weight (LBW) to be the most important cause of developmental delay in infants. Hence, the program focuses on measures adopted to reduce LBW. Some of them are :

- A simple mother oriented early intervention program which has proved to be effective and feasible.
- Stimulation and monitoring of development of children below 2 years of age using the Trivandrum Developmental Screening Chart (TDSC)
- Stimulation and monitoring of development of children between the ages of 4 and 6 using Nursery Education Seal Trivandrum(NEST)
- Education of adolescent girls on nutrition, health and family life
- Rubella vaccination to adolescent girls

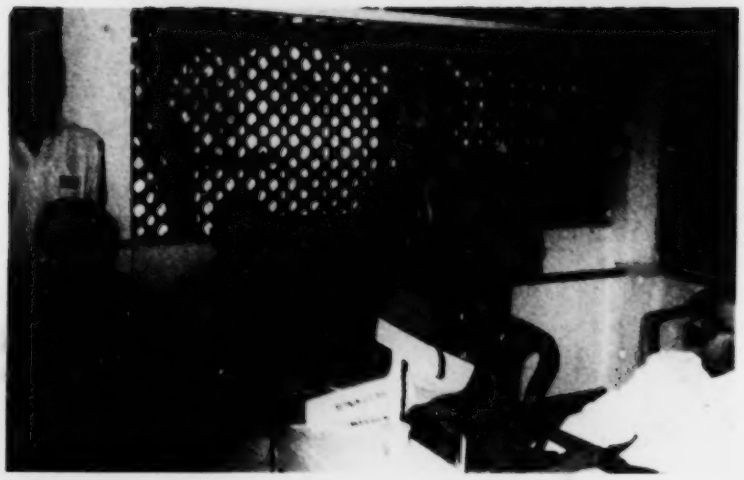
To implement these measures they have trained ICDS supervisors by getting them to do the 'Diploma in Clinical Child Development'(DCCD) offered at the Child Development Centre. These personnel will assist consultants at District hospitals to run the weekly Child Development Referral Unit (CDRU). Thus, they have established a system of referrals, starting from the anganwadi workers, anganwadi supervisors, doctors at the primary health centres and post partum units, consultants at district hospitals, and finally to the Child Development Centre at Thiruvanthapuram

OBJECTIVES OF THE PROGRAMME :

- Emphasis on prenatal care-to prevent any damage to the brain of the developing fetus.
- Reduce LBW
- Undertake resusitation programs
- Encourage breast feeding
- Prevent sexually transmitted diseases in new borns
- Early detection of developmental delays and asymmetry
- Early stimulation by training not only mothers but grandmothers as well
- Training anganwadi workers and supervisors
- Establish a good referral system

LESSONS LEARNT :

This model of using existing community resources(trained anganwadi workers and supervisors) and establishing a workable referral system has proved to be effective and successful in Kerala.



Mr. J.P. Singh - Rehabilitation Council of India answers a query.

Group II enacts "a CBR problem solving situation".

Products of SPASTN seen exhibited

One Important point to Consider:

All existing CBR programmes must take up education of adolescent girls in 'family life' earnestly.

PAPER THREE

NAME OF THE AGENCY : Young India Project

NAME OF THE PROJECT : Young India Project

LOCATION : Rural areas of Andhra Pradesh

YEAR OF LAUNCHING : 1989

ABOUT THE PROGRAMME :

Since the year 1989 Young India Project (YIP) have been training their cadres to work with people with disabilities. They work towards empowering their cadres to :

— Form advocacy groups

— Have a better social life

— Form unions

— Organise people with disabilities to form unions

— Include at least one person with disability to be a member of unions at the Mandal, District and State level.

In the year 1995, YIP encouraged people with disabilities to contest the panchayat elections. Of all the candidates they put up , 30 candiates won.

ONE IMPORTANT POINT TO CONSIDER :

The Central Act says that people with mental retardation cannot vote.

PAPER FOUR

PRESENTER : Mrs.Nandini Rawal

NAME OF THE AGENCY : Blind Men's Association (BMA), Ahmedabad

NAME OF THE PROJECT : Chanasama

LOCATION : Mehsana; 35 kms from Ahmedabad

TARGET : 124 villages

NO. OF PERSONS WITH VISUAL IMPAIRMENT SERVED : 664

FUNDING AGENCY : DANIDA

Main objectives of the Programme :

- Prevention and Care - by
  - — Networking with other agencies
  - — Inputs from core agency and field team
  - — Involvement of eye care agencies
- Comprehensive rehabilitation
  - — for all age groups
- Education
  - — Integrated
  - — Special Schools

    (more than 7000 children with visual impairment are receiving education)
- Social and economic rehabilitation
  - — Self employment
  - — availing reservation by government
- Support services
  - — Counselling
  - — training in activities of daily living (ADL)
  - — orientation and mobility training
  - — vocational training
  - — eye camps

Achievements of the Programme :

- Restoration of eye sight
- Promotion of general health
- Generate income through self-employment schemes
- Development of education and culture in the community.

Key factors for success :

- Community participation
- Training of a resource team
- Scientific and systematic approach

About BMA :

They actively network with the Ministry of Health. One of their major concerns is to empower people with disabilities. According to them a CBR model is an interface of :

- education
- agencies involved in the prevention and cure of visual problems
- comprehensive rehabilitation services

Some of their major activities are to :

- Arrange funds
- Train and develop human resources
- Monitor and evaluate programs
- Offer professional and managerial help to other agencies/projects.
- Act as a resource centre.
- Actively lobby with the government
- Select agencies that will identify persons with visual problems and offer them education, training and employment

PAPER FIVE

PRESENTER : Mrs.Ruma Banerjee

NAME OF THE AGENCY : Seva-in-Action

NAME OF THE PROJECT : Seva-in-action

LOCATION : Two Districts of Karnataka

YEAR OF LAUNCHING : 1985

FUNDING AGENCY : NORAD, Ministry of Human Resources, Government of India

OBJECTIVES OF THE PROGRAMME:

- early intervention
- early stimulation(birth to 3 years) based on Portage translated in Kannada
- inclusive education from preschool programme onwards
- Prevention of disability
- pre-vocational training
- vocational training
  - — in family trade
  - — trades available in the community
- formation of self help groups
- generating employment
  - — in existing rural development programmes
- increase the pace of rehabilitation
- to train mothers and other family members
- Developing human resources
- training teachers in integrated education
- training CBR workers

- training of personnel from the Education Department
- training anganwadi workers, health workers
- training personnel from other developing countries in planning and management of CBR.

SOME IMPORTANT LESSONS LEARNT :

— **Children with disability need trained personnel.**

— Families need to be active partners in the process of rehabilitation.

— Enlist the support of other villagers to ensure success of the programme.

— Integrated education in existing schools and preschools.

— Support of the local government bodies-panchayat, block development officers etc.

MAJOR ACHIEVEMENTS :

- Over 5000 children with disabilities have been integrated in regular school.
- Over 400 children with disabilities have passed the 7th Standard public exam.
- Over 130 children have passed the SSLC exam of which 3 were hearing impaired and 2 were visually impaired.
- CBR committees have been formed in 10 taluks of Bangalore and Kolar districts of which 7 are registered and have a legal entity.
- A six level training model has been developed for families of low literacy.

PROBLEMS AND MAJOR ISSUES:

- Sub standard government schools.
- Lack of positive attitude of policy makers towards education of disabled children.
- Prescriptive curriculum in primary schools and compulsory leveling of all children.
- Special education still based on 'labels of disability' rather than 'ability levels'. Children with disability are scattered in rural and tribal areas.
- Several limiting factors in promoting inclusive education; major among them are accessibility.
- The parents and members of the community spend every minute to sustain their livelihood; thus leaving little time available for the person with disability.
- It is important to change the attitude of the male members towards the person with disability, as this attitude greatly influences the other members of the family.
- Education is not a priority in the anganwadi's. Meeting the basic nutritional needs is still a priority.
- Need for trained personnel at the middle level management to sustain the quality of the programme.

PAPER SIX

PRESENTER	: Mrs. Aloka Guha
NAME OF THE AGENCY	: The Spastics Society of Tamil Nadu (SPASTN)
NAME OF THE PROJECT	: 'Sambhav'/DARC (Disability Awareness and Rehabilitation in the Community)
LOCATION	: Chengelpet District
YEAR OF LAUNCHING	: 1991
TARGET	: 563 Villages
FUNDING AGENCY	: UNICEF

In 1991, in response to parents' needs, SPASTN ventured into Community based Rehabilitation in semi-urban and rural areas in Chengelpet District. Today these efforts have been scaled up considerably and are operating on a daily, full time basis, through the initiatives and the training of disabled people themselves, and in some cases, through small neighbourhood centres which are being run entirely by mothers.

Some villages have set up Village Rehabilitation Committees, to rehabilitate all disabled persons in their villages through education, job-training and employment opportunities. These committees are manned by Disabled Persons, by Mahila Mandrams and by Ambedkar Youth Groups. After the local body elections, Panchayats are taking keen interest in allocating funds, space and volunteers for the necessary work in awareness-creation about disability and integration of disabled people in the community itself. SPASTN's role in these programmes has been that of CATALYSTS, creating change, both in attitudes and in environment and at least initially transferring skills in rehabilitation to local communities.

What SPASTN has developed in Chengelpet District is a Linkage Model of Early Intervention through CBR Linkage. The linkages involves the Primary Health Centres and other Government Health Outlets, as well as the Integrated Child Development Scheme (ICDS), Tamilnadu Integrated Nutrition Project (TINIP) of the State Government and the Welfare Sector. This unusual CBR model was developed with help from UNICEF and with full and equal participation of disabled people and their families.

This CBR model depends heavily on the capacity-building efforts of Village Health Nurses, Balwadi Teachers and Noonmeal Scheme workers, all Government staff, all village based and all grass root workers. SPASTN trains them in rehabilitation work, demystifying rehabilitation skills and encouraging them to INCLUDE disabled children and disability issues in all the routine activities of village life. By motivating existing Government personnel and infrastructure, and by involving disabled people, SPASTN has been able to ensure sustainability for this programme.

This was the first in India that health workers were systematically trained in rehabilitation work, which has traditionally been a Ministry of Welfare activity.

This CBR Programme has directly screened 38000 persons in 3 years, a target which would have been impossible through traditional centre based approaches. 800 Grassroot workers have been trained and 1000 persons with disabilities are either attending neighbourhood centres run by parents or are being included into the regular Balwadi and school system while some have started self-help employment schemes. Over 670 persons have been given aids and appliances including tricycles and wheel chairs, free of cost, through the Ministry of Welfare's scheme of assistance.

Key factors for success :

- Training of village health nurses, ICDS workers and TINIP Personnel.
- Early detection
  - neonatal screening
  - balwadi screening
- Early intervention
  - therapy
  - education
  - home based program
- Transfer of skills to :-
  - persons with disability
  - their family
  - the community
- Low-cost technology
- Referral system and networking
- Creating awareness

PAPER SEVEN

PRESENTER : Mr. John Patterson
International Centre for the Advancement of Community based Rehabilitation, Queen's University, Canada.

TOPIC : To Analyse the component of Attitude in CBR

A brief summary

The objectives were to study :

- The profile of CBR workers.
- The attitudes of people towards persons with disabilities and to develop a scale to measure attitudes
- The component of attitude in CBR training.

His findings indicated :

- Attitudes of people towards persons with physical disabilities were more positive.
- Attitudes of people towards persons with sensory impairment i.e. visual and hearing were less positive.
- The expectations of people in the community from CBR workers were high.

- People with a higher education have a more positive attitude.
- The formation of positive attitudes depends on:
  - contact with persons with disabilities
  - having family members or friends who have a disability
- The qualities that people in the community look for in a CBR worker are :
  - ability to treat people
  - good skills in listening and communication
  - understand the potential of persons with disability
- Generally, a CBR worker
  - is open minded
  - believes in rights issues
- Formation of positive attitudes was not related to
  - gender
  - age
  - vocation
  - martial status

He made a few suggestions to organisations involved in CBR and in the training of CBR workers.

Any curriculum must include:

- Bringing about attitudinal change
- Methods and ways of empowering people
- Ways to build the self esteem of persons with disabilities
- A detailed study of the structure of the community and politics
- Technology to educate adults
- Group dynamics
- More hours of field work, of actually working in the community.

ONE IMPORTANT POINT

Mr. Patterson stressed that we need to understand what 'empowerment' is all about. All the people talk about it all the time, but no one seems to know 'What is the psychology of empowerment?'. A lot of study needs to be done in this area.

DAY - TWO : 04.03.97

SESSION - I

Group discussions and presentation on "Objectives and selection criteria for personnel training in CBR".

This session was chaired by Dr. C. Ravindranath, Director, Government Institute of Rehabilitation Medicine, Chennai; and Co-chaired by Ms. Anuradha Mohit, Director, National Association for the Blind, New Delhi.

"CURRICULAM FOR PERSONNEL TRAINING IN CBR"

Goal, Objectives and Selection Criteria:-

Goal - To equip the members of the community to deliver comprehensive services for persons with disabilities within the community.

Objectives - At the end of the training programme the personnel will have the following skills and knowledge :

- Awareness Creation
- Assessment of needs of the community
- Resource Mobilisation
- Early detection
- Intervention programmes for all age groups
- Transfer of skills \Training of others
- Skills in forming advocacy and self help groups
- Monitoring , evaluatation and reporting .

Criteria for selection :-

- Any person with disability, family members, parents.
- Ex-service men\retired persons having experience in working with persons with disability.
- Age will not be a bar.
- Caste and creed will not be a bar.
- Motivated persons with positive attitude towards persons with disabilities and their families.
- Must have good communication skills.
- Educational qualification- Std VIII , Std X or Std XII.
- Person from all castes.

SESSION - II

Group discussion and presentations on "Development of Core Curriculum for Personnel Training in CBR".

This session was chaired by Dr.Bhushan Punani, Blind Men's Association Ahmedabad ; and Co-chaired by Mr. Methananda, Women's Development Centre, Sri Lanka.

The Day began with "Pranic Meditation". Seen in front Mr. Vijayaraghavan - Director Department of Public Health & Preventive Medicine, Government of Tamilnadu

Group Discussion

Lunch

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Core Curriculum

- Normal Child Development
- Definition and etiology
- Early detection and prevention
- Early intervention
- Functional assessment
- Educational needs
- Integration
- Training in activities of daily living.
- Communication- Augumentative and Alternate Communication (AAC)
- Aids and appliances (use and maintenance)
- Family life education
- Vocational training
- Survival skills
- Counselling
- Concessions and schemes offered by central and state government.
- Disability Act and other Legislation and policies.
- Recreation, Leisure activities.
- Providing a barrier- free environment
- Mobilising and managing resources
- Networking with other agencies.
- Record keeping , monitoring and evaluation.
- CBR models that have been field tested.
- Equalisation of opportunities.
- Employment opportunities.
- Social integration.

SESSION - III

Discussions and presentations on "Duration, Format, Training Material and Evaluation".

This session was chaired by Dr. Bhushan Punani, Blind Men's Association, Ahmedabad, and Co-Chaired by Mr. Shankara Raman, Amar Seva Sangam, Ayikudy, Tamil Nadu.

The presentation of the four groups in session one, two and three are presented below in a comprehensive form.

Duration, Format, Training Material and Evaluation.

FORMAT

- Place of training should be in the regional area.
- Duration of the course should be for 1 1/ 2 years with 6 months internship.
- This should cover 25 % of theory and 75% of practical work.
- The methodology used should be more participatory.
- Internal and external evaluation is necessary.
- Certificate to be awarded by the Rehabilitation Council of India.
- Preferance should be for sponsored candidates.

TRAINING MATERIAL :

- Curriculum (already developed).
- Faculty- should include regular and visiting.
- Infrastructure
- Teacher-student ratio must be 1:10.
- More participatory sessions to be encouraged, (case study etc).

EVALUATION :

- Internal and external evaluation is necessary.
- Evaluation to be done for 25% theory and 75% practical work.

DURATION

- Duration of course should be for 1 1/2 years with 6 months, internship.

LUNCH BREAK

"SITUATIONS IN CBR"

This was a time to bring out the creative skills in the participants and to challenge their problem solving abilities. Each group was given a "Situation in CBR" which they had to discuss in the group and come up with an appropriate solution and role play the whole situation for the other groups.

Surprisingly all the delegates participated with gusto and enthusiasm. This session seemed to bring all the delegates closer together.

The moderators were Mrs. Purobie Bose, Directo, REACH (Society for Remedial, Education, Assessment, Counselling Handicap), Cacutta and Dr.Tomy M. K, RRTC (Regional Rehabilitation Training Centre), Chennai.

ROLE PLAY

The 'CBR situations' given to the groups are given below :

Situation one :

A CBR worker from a city-based center has gone to a village in North Bihar. This village does not have any rehabilitation services. He has already been told that the Panchayat Union leader is a very difficult person and not easy to approach. However he has decided to make an attempt to meet him and convince him to initiate rehabilitation services in his village.

Situation two :

The CBR worker has reliable information that Shantamma, has a three year old boy with cerebral palsy. She therefore visits Shantamma's house only to be told "There is nothing wrong with my child". What should the CBR worker do now?

Situation three :

Mahesh is a twenty year old young man, affected in both lower extremities by polio. He has finished tenth standard. He is the only child of Hariharan and Kumari. They live in a farming village. His father expects him to help in the farming activities. Mahesh uses a pair of crutches to walk within the village. But he cannot reach their family land as he is not able to walk on the narrow bunds surrounding the fields. What is the solution to this problem?

Situation four :

Gowri has a two year old girl, Vasanthi, who is visually challenged. Gowri has been deserted by her husband. She is a daily-wage earner and lives with her elderly mother whose sight is failing. Gowri is unable to participate in the rehabilitation program as she is the sole bread-winner. What are the options for Vasanthi's rehabilitation?

CURRICULUM IN DETAIL

MENTAL RETARDATION

I. NATURE :-

- Normal Child Development.
- Meaning and definition of Mental Retardation.
- Characteristics,types and degrees.
- Associated conditions

II. CAUSES OF MENTAL RETARDATION :

- Preventive measures

III. MANAGEMENT AND FOLLOW UP :

- Early detection, assessment and intervention.
- Education and training (need based)
  - — Preschool
  - — School and prevocational.
  - — Vocational and survival skills
  - — Integration in the community.
  - — Community living during adulthood.
  - — Sexuality and exploitation.

IV. COMMUNITY AND GOVERNMENT SUPPORT :

- Family support and training.
- Referrals.
- Self Help and mutual support groups.
- Social benefits.
- Legal aspects.
- Lobbying and advocacy.

MOTOR DISABILITY

- Basic Anatomy / Physiology / Pathology of movement disabilities.
- Prevention of movement disabilities- primary, secondary and tertiary levels.
- Basics of Physio\Occupational therapy, ADL training - (exclude Electrotherapy).
- Early detection and intervention.
- Availability of appliances - fabrication and maintenance of simple, appropriate aids.
- Post burn sequalae.
- Basics of hereditary diseases and congenital disabilities.
- Awareness about HIV related disability.

VISUAL IMPAIRMENT

I. Early identification and early intervention.

II. Classification of Visual Impairment.

— in relation to functional and training skills.

- Low vision
- Blind

— in relation to etiology.

- Congenital
- Adventitious

— functional assessment procedures.

III. Visual Impairment and Implications:

- Orientation and Mobility
- Education
- Vocational training
- Placement
- Sports and recreation
- Language development
- Socialisation, participation and equality.

IV. Education and Communication Skills:

- Education
- Early stimulation
- Sensory training
- Concept development
- Language development
- Social development
- Orientation to various educational models.
- Communication
- Introduction to Braille

V. Vocational Rehabilitation.

- Vocational guidance
- Skills training
- Resource mobilisation
- Need -based economic rehabilitation.

VI. Aids and Appliances.

- Mobility aids
- Educational aids
- Functional aids
- Low vision aids

VII. Awareness.

- Rights, potentials, facilities and schemes for the visually impaired.
- Public awareness- promoting positive attitudes towards persons with disabilities.

VIII. Family involvement and adjustment:

Family involvement :

- Guidance
- Parental training

Adjustment :

- Orientation and mobility
- Activities of daily living
- Crisis intervention and counselling.

IX. Empowerment

- Leadership development
- Community organisation
- Self-help groups

SPEECH AND HEARING

I. HEARING :

- Importance of hearing, hearing mechanism, sound and measurement.
- Types and degrees of hearing loss, (conductive, sensory neural, mixed), Impact of hearing loss
- Psychological problems.

II. CAUSES AND PREVENTION :

- Prevalance
- Methods of early identification- screening of at risk babies and children.

III. INTERVENTION - BASIC AUDIOMETRY :

- Interpretation of audiograms
- Multidisciplinary approach- AWW, PHC, Pre-school teachers, panchayats, family members.
- Types of hearing aids : how it works, basic maintenance and repair, making ear moulds and fitting of ear moulds.

IV. AUDITORY TRAINING :

- Sound awareness, gross and fine sound discrimination, speech sound discrimination.
- Speech reading skills : tips for effective speech reading, speech correction.
- Sign language, finger spelling.

V. SPEECH IMPAIRMENT :

- Concept of communication, language and speech.
- Factors responsible for speech development.
- Causes for delayed speech and language development.

VI. TYPES OF SPEECH IMPAIRMENT :

- Misarticulation
- Voice disorders
- Stuttering
- Delayed speech and language development.

VI. INTERVENTION :

- Auditory training
- Use of mirror, household materials for speech and language stimulation.
- Use of flash cards.
- Prolongation method for stammering.
- Use of non-verbal communication.
- Vocational training
- Involve mothers in rehabilitation programmes.

NOTE:- The Syllabus should also include

1. Social Work methods
   - Case work
   - Group work
   - Community dynamics
   - Community organisation
     - — Social action
     - — Advocacy
2. Basic Managerial Skills:
   - Planning
   - Organising
   - Documenting
   - Reviewing

The Presentations of session one evoked a group discussion and the participants were divided about a CBR worker, should the person be literate or could he be non-literate too.

Some highlights of the discussion :

- being non-literate should in no way undermine the intelligence of the person, but it is important for the CBR worker to be literate, keeping in mind the nature of work he / she is expected to perform.
- Non-literate persons in the community can be volunteers in the CBR program.
- Literacy is 'empowerment' of individuals and this should be encouraged as the country is investing enormous sums of money on advocating literacy.
- An individual CBR program should have the flexibility to choose persons who would be CBR workers-be they literate or non-literate.
- A literate person in a CBR program has more acceptance and respect in the community.

Consensus : Opinion :

A CBR worker should be literate, and have the ability to read and write. This will also help to maintain the quality of CBR work.

Following this, a synthesis report was presented by Ms. Nalini James and Ms. Sheba Thomas from the Spastics Society of Tamil Nadu, Chennai.

This session was chaired by Ms. Anuradha Mohit, Director, National Association for the Blind, New Delhi and Co-chaired by Ms. Nandini Rawal, Blind Men's Association, Ahmedabad.

This brought to an end the proceedings of Day Two.

DAY THREE 05.03.97

All the delegates were taken to visit the CBR programmes of The Spastics Society of Tamil Nadu at Tiruvallur (earlier Chengelpet) from 8:30am to 9:00pm.

This brought the three day workshop to an end.

Co-presenters
Dr. Krishna Prasad of Nepal
Mr. John Patterson of Canada

Presenting the BMA Model
Ms. Nandini Rawal - Ahmedabad

Chairing a session
Dr. P. Chandra - Madras
Ms. Anuradha Mohit - Delhi

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BENEFITING THE ECONOMY BY EMPLOYING PEOPLE WITH DISABILITIES

Paper presented at Rehabiliation India National Conference March '97

Ms. Nandini Rawal,
Project Director,
Blind Men's Association

Dates of Actual Presentation : 22.3.97

Recognition of the Rights of Disabled People

Any Paper that deals with the employment of persons with disabilities has to first begin with highlighting the aspect that a person with a disability is first and foremost a human being. He has the same aspirations, dreams, as that of a non-disabled person, but more importantly, he has the same rights. The United Nations and its specialized agencies have been taking tremendous interest in the prevention of disability and complete rehabilitation and education of all categories of disabled persons. Because of this interest, significant advances have, in recent decades, taken place in the field of prevention, education, rehabilitation and research at the national and international levels (Desai, 1984).

The General Assembly of the United Nations also recognized the rights of disabled persons by adopting the Declaration on the Rights of Disabled Persons have the inherent right to respect for their human dignity; right to enjoy a decent life; have the same fundamental, civil and political rights as their fellow citizens; and are entitled to the measures designated to enable them to become as self-reliant as possible (Desai, 1984). The Universal Declaration of Human Rights and the International Convenants on Human Rights have clarified that the rights enshrined in these instruments are for all human beings, irrespective of any distinction based on race, colour, sex (and disability).

Right to Employment : The end product of vocational rehabilitation is the resettlement or re-entry into active economic life-in remunerative work which is not only suited to his residual capacities but makes the best use of his skills. Disabled persons have the right to education, vocational training, counselling, rehabilitation, placement and other services which will enable them to develop their capacities and skills to the maximum and will hasten the process of their social integration and comprehensive rehabilitation (Desai, 1984).

International Labour Vocational Rehabilitation (Disabled) Recommendation Act 1955 says :

- disabled persons should be afforded an equal opportunity with the non disabled to perform for which they are qualified.
- they should have full opportunity to seek suitable work with employers of their own choice.

Responsibility of the State : Desai (1984) stresses that it is responsibility of the state and the community to ensure that those who are denied by nature the precious gift of sight or an important limb or faculty of the body are not placed at a further disadvantage by denying them equal opportunities and the normal facilities of primary health care, education, vocational training, employment and social life available to their fortunate brethren.

Desai (1984) goes a step further and suggests that the greater the disability, the greater should be the responsibility of the State and the community to provide adequate education, training and other facilities which would minimize the adverse effects of disability, develop their residual sensory and other functions as normally as permitted by the severity or the extent of their disability.

Recognition in India : The Article 45 of the Constitution of India enjoins on the State to provide universal, free and compulsory education to all children upto 14 years of age. The mention of all children by implication also includes the disadvantaged ones including the disabled.

The country has witnessed phenomenal expansion of education opportunities in the post-independence period. Disabled children, however, have not benefited substantially from this growth in educational facilities. The Government of India, therefore, has resolved to make special efforts to equalize educational opportunity for the doubly disadvantaged group of disabled children to achieve the goal of education for all.

Importance of Contribution to Economic Growth

The primary goal of economic growth is to increase the welfare of people. Welfare may be increased by producing more goods and services and distributing the same more equally among the people. Production of goods and services can be increased by the fuller and better utilization of all productive resource, and by augmenting the productive capacity of resources by research and development (Gounden, 1987).

This assumes, naively, that all persons in the working age produce to the utmost of their ability. The disabled persons, however, form a significant part of this work force. When disability reduces capacity to earn, or prevents jobs being available, it is a loss to the national exchequer. It can place heavy burdens on the persons himself, his caretakers and economic performance of the caregivers and ultimately society.

Over the years, importance of contribution of each and every although the industrial revolution had inducted an element of economic competition wherein earning capacity determined the survival and quality of life an individual qualified for, the war ravaged economies accentuated the process (Jangira & Mani, 1990).

The situation demands that each individual must contribute economic growth. The education and training of each and every individual leading to gainful employment became indispensable. Every individual including the disabled has come to be recognized as a human resource. Naturally, the efforts to make every disabled persons independent economically through programme of education, habilitation and rehabilitation was recognized (Jangira & Mani, 1990).

Economic Gains of Employment : The point for consideration is whether we are going to allow an army of some 500 million disabled persons - 1000 million at the turn of the century - to remain unproductive and dependent fully or partially - on the state or on private or family charity or whether we are going to make an all out super human effort to educate, train, develop and economically resettle them to become productive, self reliant and self respecting, independent citizens living a full normal life and enjoy all fundamental rights, freedoms and, above all, human dignity (Desai 1984).

The non-economic or intangible gains of gainful employment are also equally important changes in the capability of care givers, the satisfaction of working on the part of the persons with disability and more important the demonstration to a sceptical society.

Effect of Impairment : A United Nations Expert Group Meeting on the Economic and Social Implications in Rehabilitation Services concluded that at least 25 per cent of any community is thus directly affected by the existence of impairments. Obviously, it is more economical to educate, train and assist disabled persons with employment and self employment and to enable them to earn their living. Providing life-long rehabilitative services is not only prohibitively costly but also inhuman (Desai, 1984).

Economic Loss : The National Programme on Control of Blindness (1992) has published statistical estimates on total economic loss to the nation on account of blindness :

No. of Visually impaired Persons (1989)	:	12 million
Maintenance Cost (Rs. 300 p.m. for 10 years)	:	432,000 million
Loss of Production (Rs.600 p.m. for 10 years)	:	864,000 million
Total Economic Loss	:	12,960 billion

One can easily imagine the extent of economic loss when we consider all the disabilities collectively.

Thus the economic loss to the nation on account of disability alone is 10 billion rupees per day.

Investment in Training - A Human Resource Development : At present, only 8 per cent disabled children receive formal education and training (Advani, 1993). Cheah (1963), UNESCO (1988), Bowman (1990) and Brohier (1990) also support the contention that facilities for vocational training and employment are quite limited in number and support services are painfully inadequate. Providing training and employment to remaining 92 per cent disabled persons would entail colossal investment in creating infrastructure, developing organizational network, training the teachers and other specialists and incurring huge recurring expenditure on staff salaries, educational material and incidental expenses.

Economics of Education and Training : The concept of economics of education is three decades old, commencing with T.W. Schultz's (Association). Yet the concern for the most effective use of resource in education, training and employment is more recent and may be traced to the financial and economic crisis of mid seventies. Since then, there has been much caution for committing resources to education among all sections of society. The effectiveness of resource utilization in education is an essential factor for justifying enhanced resource allocation for education of a particular segment of society.

Human Resource Development: The human resource development approach has a philosophy of its own. Each and every individual has to be developed for optimum contribution to the pool of human capital-social, cultural and economic. In other words, every individual has an opportunity for better growth and development.

The development of human resources is the cardinal objective of education in a developing economy. It is this which makes education, training and employment an investment and it is the maximization of returns from this investment that determines its contribution to the development of human resources and, therefore, to economics and social growth.

Human Capital : In fact, the concept of human capital was rediscovered in late 1950s; it was a rediscovery in the sense that eminent classical economists like Adam Smith, Irvine Fisher, Alfred Marshall and others saw the relevance of education in what they had written (Gounden, 1987). Smith included all the acquired and useful abilities in fixed capital; he considered dexterity of a workman as similar to a machine or an instrument of trade Marshall observed that knowledge is the most powerful engine of production and 'the most valuable of all capital is that production' and 'the most valuable of all capital is that invested in human beings'.

According to Gounden (1987), human capital gained such popularity among economists in the 1960s and 1970s that it became one of the fastest growing subjects. A major part of human capital is formed by education and training and the rest by medical care. The attitude of planners has changed; instead of considering training for employment as consumption they regard it as investment. Most human capital economists consider that education has both consumption and investment value. Most of studies have, however, treated education as investment.

Returns in the Long Term : Shah (1993) examines contribution of education to human resource development treating the theory of the loss of potential social products, the existing human capital should be tapped even by sheltering some social programmes from short term

economic pressures. It implies that even if the education and training of disabled persons appears to be more expensive as compared to that of the normal children, it is worth investing in this component of human resource as it is definitely going to yield commensurate returns in the long run.

Expenditure on Employment - oriented Training - An Investment : Dhar (1991) also considers expenditure on education as an investment which yields returns after quite a long lag. According to Aggarwal (1988), the provision of education, health care and nutrition is now considered a precondition for the proper development and utilization of human resources in sustaining the process of development. Hence education and training leading to employment of all children including the disadvantaged ones is essential for achieving this cherished goal.

Investment in Training of Disabled Persons : Goel (1990) has calculated rate of return on the investment in the disabled with the alternative assumption about contribution of vocational training to the life time net benefits stream. Without going into the statistical jugglery, the conclusion is that the investment in special education and vocational training for the disabled is economically justified. It implies that the enrollment in the institutions for the disabled would increase if better information were provided and all financial constraints of the institutions were removed.

Thus if the state governments were concerned about equalizing opportunities to the disabled with normal persons, it could raise private rates of return even higher by making more generous grants to them. In this way, a case can be made, even on economic grounds, for additional public expenditure on promoting education and vocational training of the disabled (Goel, 1990).

Incremental Earnings

It has been advocated by the researcher that incremental earnings represent the effect of education and training. Various factors like mental ability, achievement drive, social class, ethnic origins, education of the parents and their own educational qualification, the size of the family, etc. - all have some independent effect on the earnings and are also correlated with education and vocational training (Goel, 1990).

Incremental Earning in the Indian Context : According to Mark Blaug (1969), in India additional schooling can be assumed to account for a half to two-thirds of the incremental earnings. Goel (1990) feels that higher earnings associated with vocational training may not be solely due to the investment role of vocational training, rather these may be due partly to the fact that quite a few of the disabled have been eliminated in the process of 'screening' as they did not have the prescribed 'vocational' training credentials. Taubmen and Wales (1969) have also established that upto one half of the earnings are due to 'screening' role of education.

Not many studies, however, are available on estimates of cost-benefit ratio, cost effectiveness or profitability of employment oriented vocational training in India. Studies of Gounden (1992), however, establish that primary education is the most profitable investment while education in the art stream at the university level is the least profitable. If a 12-15 per cent interest rate is considered, then most of education seems to have a favourable rate of return. In case of employment-oriented training, the returns are likely to be higher.

Incremental Earning of the Disabled : According to Goel (1990), the appropriate education and training has a definite role to play in the incremental earnings of the disabled. It will result into adequate returns on investment which justifies promotion of education and training of such disadvantaged groups.

Desai (1984) also considers the investment in development of human resources, especially in developing disabled persons , is a worthwhile investment which, in course of time,

would pay very rich dividends and would reduce the burden on the state in maintaining expensive lifelong rehabilitative services for a large number of disabled persons. Appropriate education, intensive vocational training leading to employment or economic resettlement would, in due course, generate new purchasing power and bring in more revenue for the State if disabled persons are enabled to earn a decent living.

In course of time they become independent members earning their own living and supporting their own families. They would live with human dignity and worthy. They become productive and contributive members of society. In various ways, and in divergent fields, they enrich communities and substantially contribute to socially and economic development. The gains in human terms are simply immeasurable. Thus, even from purely an economic angle, the investment made in education, training and developing disabled persons is a worthwhile and wise investment which no government can afford to ignore.

Efficient Use of Resources

An important aspect of cost effectiveness is improving the delivery of services and ensuring convergence of education and other related services at the delivery level as well as different levels of planning (Ayyar, 1993). The same logic is true while selecting and promoting a mode of education or training of the disabled. The cost effectiveness and accountability should be the deciding factors while selecting the mode of their education.

Restoration of Human Dignity

Besides, education and rehabilitation reduces, to the extent possible, unnecessary human suffering. It restores human dignity of the individual. These advantages are very positive. They just cannot be evaluated in monetary terms alone. Rehabilitation adds to sum total of human happiness. The financial investment made in education, training and rehabilitation of disabled persons repays itself many times over (desai, 1984). It also help to integrate disabled persons in the national mainstream.

When persons feel valued and accepted by the other, they are more likely to value and accept themselves (Tuttle, 1987). The social identities of individuals reflects the perceptions of significant others (Rogow, 1988). Glick (1980) suggests that feedback from the environment is the most important characteristics of ecosystems. The ecosystem is comprised of all the interactions individuals have with their environments. Environments have profound effects on self-identity. As school and training centre environments have a profound effect on the way children come to perceive themselves, education and employment-oriented training is likely to enhance self-esteem, self-respect and human dignity of the individual.

Equity and Social Justice :Goel (1990) also advocates that if the rate of return on investment in the education and training of the disabled were low, they have every right to utilize the resources of the state on social grounds. Once the investment and the economic viability from the investors point of view is justified, it makes better sense to promote it on social grounds as well. Capt. Desai (1984) also supports this contention and concludes that education of disabled persons is justified from the point & view of equity as well as social justice. (Ayyar 1993) also concludes that efficiency and effectiveness should not be at the expense of equity. An essential component of the management of change is to sensitize the system to educational needs of women and disadvantaged groups (including disabled persons), to the empowering role that education and training can play.

Equity and Quality :The shift to quality and equity posses a great challenge to existing educational administration. Such shift is no less resource intensive than quantitative expansion of institutions. Hence , even while there is a shift of resources towards elementary and adult education, resources should be located and provided for other sector of education (including special education of disabled children) and training as envisaged in the National Policy on education, 1986. (Ayyar, 1993).

Yet another dimension of the concern for rehabilitation and employment of disabled persons refers to the quality of life. Education and training being one of the essential inputs to the quality of life, its universalization among disabled persons also assumed significance (Jangira& Mani, 1990). During late fifties and sixties, the improvement of quality of life for the disabled persons as a part of overall improvement of quality of life of all citizens became one of the goals of national development. So development of disabled persons as human resources came to be linked to the quality of life.

Need for Integration : The indicators of integration are that disabled persons enjoy the same right as the rest, have equal opportunity for growth and development in environment conditions available to the rest, have access to quality of life like any other citizen, and are treated as equal partners in the community. The process begins by social proximity, i.e. reduction of physical distance. It continues with mutual sharing of the physical results in social integration in which groups become equal partners in the community (Jangira & Mukhopadhyay, 1987).

Selective Placement : Advani (1993) advocate that the quality of education that a disabled child receives also depends on selective placement . A child must be carefully assessed before it is decided to place him in a special school, an integrated setting, in a non - formal education setting or in a setting where he can benefit from distance learning. According to Rogow (1988) placement is generally determined by the amount of specialized education instruction needed. The principle of selective placement in respect of various modes of education must be regarded as a cardinal principle in improving the quality of education to be imparted to disabled children.

Patel (1987) establishes that economical rehabilitation of disabled persons would generate a new urge and an inspiration for a better living among their family members, a desire to improve their material conditions and have more constructive outlook towards their future. The education would thus promote a meaningful beginning of true rehabilitation.

Summary

The United Nations have duly recognized the human rights of disabled persons including the right to economic independence. Education, training and employment are definitely instruments of growth in a developing economy. The implications of these growth in a developing economy. The implications of these observations are equally effective in case of all segments of society including the disabled ones. It is the extent of knowledge, skills and aptitude which matters and not the physical abilities of the individuals. Thus the education and employment oriented training of the disabled a vast human resource - is also an equally important investment.

The most significant development in the field of education of disabled children in India is its inclusion in the National Policy on Education (1986). The policy lays emphasis on the removal of disparities and the need to equalize educational and training opportunity for all. The effectiveness of resource utilization in training is an essential factor for justifying enhanced resource allocation. As the ultimate objective is enabling the individual to the optimum level, the logic of human resource development is applicable to all persons including the disadvantaged ones.

The expenditure on employment oriented education and training constitutes an important form of investment in economic development. The investment in special education and vocational training has a definite role to play in the incremental earnings of the disabled. It will result into adequate returns on investment which justifies promotion of education and training of such disadvantaged groups. It would not only bring about economic development but also enhance equality. The education, training and employment of the disabled are thus justified from the point of view of equity as well as social justice.

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COMMUNITY - BASED REHABILITATION FOR PERSONS WITH DISABILITIES

BRIEFING MATERIAL FOR INDIA

This paper was presented, by Dr. Einar Helander at an UNDP sponsored conference in Delhi on 18th, Jan 98.

It is reprinted here in public interest and for no other purpose.

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A. BACKGROUND

1. Prevalence of disability in India

The prevalence of disability in India has been studied in several surveys. These have been built on questionnaires either administered at censuses, or as special studies.

Questionnaires are, however, unreliable as sources of information. Many people are reluctant to reveal that a member of the family is disabled or may be ignorant about disability. An appropriate survey of the prevalence of disability must build not only on questions, but also on examinations and observations of each household member. For these reasons, most available surveys from India are under-reporting the problem.

International data exist, and it is suggested to use these for the time being. These data are the basis for the calculations made in Fig. 1.

It may be seen from Fig. 1 that the prevalence of severe and moderate disability in India may be estimated at about 4.6 percent or 4.3 crores. Besides this group, there is a large number of persons with a slight disability, many of whom, at present, are excluded from education, training, jobs and access to other development projects. Fig. 2 show the projected number of people with a moderate and severe disability by the year 2020. By this time, India's population is expected to increase from 93;6 to 132;7 crores and the number of disabled people to 7.8 crores, or by 80 per cent. This corresponds to 5.4 per cent of the population.

2. Types and causes of disability

Of all people with a severe or moderate disability, about 40 percent have difficulties moving (caused by polio-myelitis, spasticity trauma, arthritis, muscle disease, stroke, congenital conditions and other health conditions). Some 15 percent have serious impairment of the sight or blindness (caused by e.g. cataract, vitamin A deficiency, measles and other infections, or glaucoma). Another 15 percent have a mental handicap, and about 10 percent severe hearing impairment and/or difficulty speaking. For the remaining group the disability has been caused by a variety of other health conditions, such as epilepsy, leprosy or chronic mental disease. As infant and child mortality decrease in India, we can expect a higher survival rate of children with mental handicap and/or spastic disease. On the other hand, polio as a cause of disability may be eradicated in the foreseeable future.

When setting up a service delivery system the needs of all the different groups of disabled persons at all ages should be taken into consideration.

Figure 1 : The 1995 prevalence of severe and moderate disability in India. Estimations based on international data.

Age groups	Prevalence percent	Population in India Lakhs	Disabled population in India Lakhs	
0-4	1.3	1174	15.3	
5-9	2.5	1092	27.3	70.3
10-14	2.7	1029	27.7	
15-19	1.9	909	17.3	
20-24	2.0	862	17.2	55.4
25-29	2.3	777	17.9	
30-34	3.2	689	22.0	
35-39	3.7	601	22.3	
40-44	4.4	501	22.0	148.7
45-49	5.8	410	23.8	
50-54	7.7	345	26.6	
55-59	10.8	296	32.0	
60-64	15.1	244	36.8	
65-69	18.3	182	33.3	
70-74	25.5	122	31.1	158.3
75-79	37.6	73	27.4	
80+	56.0	53	29.7	
	Total	9357	432.7	
			4.6%	

Figure 2 : The 2020 prevalence of severe and moderate disability in India. Estimations based on international data.

Age groups	Prevalence percent	Population in India Lakhs	Disabled population in India Lakhs	
0-4	1.3	1031	13.4	
5-9	2.5	1104	27.6	72.0
10-14	2.7	1147	31.0	
15-19	1.9	1161	22.1	
20-24	2.0	1154	23.1	71.0
25-29	2.3	1123	25.8	
30-34	3.2	1063	34.0	
35-39	3.7	998	36.9	
40-44	4.4	874	38.4	279.5
45-49	5.8	820	47.6	
50-54	7.7	725	55.8	
55-59	10.8	619	66.8	
60-64	15.1	505	76.2	
65-69	18.3	377	69.0	
70-74	25.5	259	66.0	354.2
75-79	37.6	166	62.4	
80+	56.0	144	80.6	
	Total	13270	776.7	
			5.85%	

3. Policies

3.1 National Policy Background

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) act 1995 received the assent of the President on the 1st of January 1996.

Chapter 1 mentions that the Act extends to the whole of India, except the States of Jammu and Kashmir. This is followed by a set of definitions.

Chapter 2 deals with the Central Co-ordination Committee and the Central Executive Committee.

Chapter 3 describes the composition and functions of the State Co-ordination and the State Executive Committees.

Chapter 4 calls upon the Appropriate Governments and the local authorities-within the limit of their economic capacity and development - to take certain steps for the prevention of the occurrence of disabilities.

Chapter 5 deals with education (see Annex 1, Para 26-31).

Chapter 6 deals with employment (see Annex 1, Para 32-41).

Chapter 7 concerns aids and appliances to persons with disabilities and Schemes for preferential allotment of land for certain purposes (see Annex 1, Para 42-43).

Chapter 8 covers the subject of non-discrimination in transport, roads, buildings and in Government employment (see Annex 1, Para 44-47).

Chapter 9 deals with research and financial incentives to Universities to enable them to undertake research.

Chapter 10 concerns the procedures for recognition of institutions for persons with disabilities.

Chapter 11 covers the institutions for persons with severe disabilities.

Chapter 12 deals with Chief Commissioner and with the State Commissioners (see Annex 1, Para 60-65).

Chapter 13 concerns social security and directs Appropriate Governments and local authorities to undertake rehabilitation, provide insurance schemes for employees with disabilities and unemployment allowances.

Chapter 14 concerns miscellaneous administrative subjects.

This Act is the most important document in the country, spelling out the benefits and programmes that disabled persons should receive, and requesting the State Governments and local authorities to be responsible for all the necessary action.

3.2 International Policy Background

There are two recent international policies of importance to the development of services and opportunities for persons with disabilities.

- the U.N. Convention on the rights of the Child (see Annex II).
- the U.N. Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. (see Annex III); India is a signatory of the Child Convention and has participated actively in the formulation of the Standard Rules.
- the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region, of which India is a signatory.

4. Definitions

4.1 Definition of a person with a disability

There are many definitions of the term "disability". Internationally, disabled people are defined as having functional limitations and/or activity restriction that may cause a physical, a psychological, and/or an economic dependency on their families or communities.

According to the Indian Act "a person with a disability" means "a person suffering from not less that forty per cent of any disability as certified by a medical authority. According to the law the following conditions are recognised as disabilities.

- blindness (visual acuity in the better eye of less than 6/60 using corrective lenses);
- low vision (a person with impairment of vision even after treatment and using corrective lenses, who uses or is potentially capable of using vision for the planning or execution of a task with appropriate assistive device);
- leprosy-cured (a person cured from leprosy, who still has a loss of sensation in hands or feet and/or loss of sensation and paresis in the eye and eyelids, or manifest deformity and paresis but having sufficient mobility in their hands and feet to engage in normal economic activity or extreme physical deformity as well as advanced age which prevents him from undertaking any gainful occupations);
- hearing impairment (a loss of sixty decibels or more in the better ear in the conversational range of frequencies);
- locomotor disability (disability of the bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy);
- mental retardation (arrested or incomplete development of the mind of a person, characterised by subnormality of intelligence);
- mental illness (any mental disorder other than mental retardation).

The Indian Act concerns the persons with the conditions listed above.

4.2 Definition of rehabilitation

Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life, and self-actualisation.

Rehabilitation is more than just training disabled people. It also includes interventions in the general systems of society, environmental adaptations, and protection of their human rights.

It is the duty of the government of each country to protect the human rights of their communities and of the individual citizen. Disabled people shall enjoy the same rights as non-disabled persons - there must be no exceptions. Authorities may have to pay special attention if disabled persons are to be ensured access to health and social services; to educational and work opportunities; to housing, transportation and buildings; to information; to cultural and social life; including sports and recreational facilities, as well as representation and full political involvement in all matters concerning them.

5. The strategy of community-based rehabilitation

"Community-based rehabilitation (CBR) is a strategy for enhancing the quality of life of disabled people by improving service delivery, by providing more equitable opportunities and by promoting and protecting their human rights."

Community-based rehabilitation builds on community initiatives and local resources. It seeks to mobilise disabled people and their families and to promote the widest possible inclusion of them in mainstream rural and urban development. The community initiatives needs to be backed up by public, technical and administrative support.

The reasons for the setting up of a CBR system in India are the following. Until now, NGOs have been the main provides of services for disabled people. But they have only been able to cover some 2-3 percent of the needs. NGOs are, to a very large extent, based in urban areas - thus the rural population of India is barely reached. A CBR system has been shown to have low costs, yet provide effective results. And finally, through a system that builds on their inclusion in regular schools, mainstream training, employment and other development schemes, disabled people with be better integrated in their societies. Their dependency on others will decrease and their abilities for productive work fully utilised. CBR is a strategy that is already applied with success in India and in a large number of other countries.

6. Needs of disabled people

The basic needs of disabled people are the same as for all other citizens. Most of the services they need can be effectively provided to them through the public service system open to everyone. Some of the training must, however, be made on an individual basis. This concerns especially the **functional training** in daily life activities (eating, dressing, washing etc.), mobility (including provision of walking aids, appliances, etc.), communications and behaviour. Such training will, in the CBR system, to the largest extent possible be carried out at home with the active participation of the disabled person and the family. As regards **education**, most disabled children can attend regular schools. Adolescents are mostly able-with some environmental adjustments - to attend mainstream **ability training**.

The provision of such services serves to prepare people with disabilities for their future participation in mainstream development schemes, such as those available in India through the Ministry of Rural Development.

7. The inclusion of disabled people in decentralised rural development schemes for poverty alleviation

The rural areas in India account for about 75 percent of the population. This population has "a much lower level/than the more affluent population/of per capita income and consumption as well as poorer access to education, health, water supply and other essential services and amenities. The development of rural areas and rural people, particularly the scheduled castes/scheduled tribes, weaker sections and the people below the poverty line and more specifically, the alleviation of rural poverty continues to be the central concern of development planning in India".

India has among the highest prevalence of poverty in the world; the World Bank estimated in 1985 that there were about 420 million poor in India (45 per cent of the population), and among them 250 million (27 per cent) were extremely poor; (the poverty line in 1985 PPP dollars was $ 275 per capita for the extremely poor and $ 370 per capita per year for the poor, the official 1995 rate in India Rs. 11.000).

In India there are a number of important schemes designed to assist especially the poor, such as those related to rural development. The central budgetary allocation for the Jawahar Rozgar Yojana Programme was, for 94/95, Rs.3855500 lakhs. Expenditure is shared between the Centre and the State on a 80/20 basis. Within this context provisions are already made for the participation of persons with disabilities in rural development. It is recommended to allocate at least 3 per cent of these funds for poor persons with disabilities.

It is, however, easy to understand that disabled people who have not received any preparation in the form of functional training, schooling or ability training will often be excluded from participation in rural development schemes. Sometimes this outcome is the result of prejudice: it is the presence of disabilities that is seen as an obstacle. Instead, what should count, should be the abilities that the disabled person has, but these are often overlooked. For these reasons most disabled persons remain excluded and thus become unnecessarily dependent on others. Even when disability strikes adults, it is common to see that efforts to re-integrate them are not made - in spite of the evidence to the contrary - as it is generally believed that rehabilitation will not lead to the restoration of the working capacity.

The image of disabled people as the poorest among the poor is confirmed by a recent study of how villagers perceive poverty among their members. Table 1 shows that disabled people are seen as the most deprived and poor by other local people.

Table 1. Perception of disabled people as the poorest among the poor

A short illustrative list of some criteria used by local people in "ill-being" grouping and ranking a selection from sources in Asia and sub-Saharan Africa (those on the top of the list are seen as worst off). Compilation by R. Chambers, 1995, ibid.

- Disabled (e.g. blind, crippled, mentally impaired, chronically sick)
- Widowed
- Lacking land, livestock, farm equipment, grinding mill...
- Cannot send children to school
- Having more mouths-to-feed, fewer hands-to-help
- Lacking able-bodied members who can fend for their families in the event of crisis
- With bad housing
- Having vices (e.g. alcoholism)
- Being "poor in people", lacking social supports
- Having to put children in employment
- Single parents
- Having to accept demeaning or low status work
- Having food security for only a few months each year
- Being dependent on common property resources

Sources include Sarah 1992, Reed Barna 1993, A Rajaratnam and J. Rajaratnam pers. Comm. 1993.

The objectives of the Government of India's programme for rural development (Jawahar Rozgar Yojana) is to generate "additional gainful employment for the unemployed and underemployed men and women in rural areas". This objective will be met through:

- "Creation of sustained employment by strengthening the rural economic infrastructure."
- "Creating community and social assets."
- "Creating assets in favour of the rural poor for their direct and indirect benefit."
- "Positive impact on wage levels."
- "Overall improvement in the quality of life in rural areas."

The financial resources for rural development are substantial and at the disposition of the Panchayat Raj institutions, following the 73rd Constitution Amendment Act of 1992. The objectives of the Amendment are :

a) "To place more and more power in the hands of the rural people to determine their own destiny

b) "To enhance the capabilities of the rural people to involve themselves in the planning from below

c) "To decentralise execution of all kind of development activities with effective participation of peoples, and

d) "To orient development administration based on the philosophy of popular participation".

There is no doubt that the inclusion of disabled community members in the rural development schemes is of utmost importance.

B. STATE LEVEL PROGRAMME

1. Objectives

The development objective of a State Plan for CBR may be formulated as follows:

"to promote a development that will eventually lead to equality and full participation of persons with disabilities in community life".

The detailed objectives for a State programme for people with disabilities would be to provide the resources needed to :

1. enhance disabled people's participation in mainstream sustainable human development programmes.
2. implement a community-based rehabilitation programme that will be responsible for the services and initiatives necessary to prepare people with disabilities for their participation in community life;
3. promote and protect the rights of disabled citizens.

2. Outputs

In relation to the immediate objectives there will be the following outputs.

1. training of all technical and administrative personnel and provision of all other resources needed for the implementation of the programme.
2. the setting up of a system for delivery of services that will reach the disabled citizens. This system will work at all levels from the local Panchayats to the State, in full co-ordination with other sectors of public services, such as education, health, labour, rural development etc.
3. elimination or reduction of the physical, psychological, economic and social dependency of persons with disabilities.

3. Proposed strategy for delivery of services and improved access to development opportunities for persons with disabilities

3.1 Strategy regarding personnel at State, District and Taluk levels

It is a common experience that in spite of all hypothetical opportunities available to disabled people, not much will happen, unless a special effort is made to include them. For this

reason it will be necessary to consider the setting up of a service delivery system that will look after their interests.

If we want services to reach disabled people, support is needed from the community leadership and from personnel that has been prepared to take responsibility for the action needed. An example of such personnel is the Multipurpose rehabilitation worker (MRW), working at the Taluk Level.

The recent planning of a special course plan for MRWs is related to the Rehabilitation Council Act of 1992. This act states that organisations that deliver services for persons with disabilities, will employ only personnel that meets the Council's requirements for competence.

In 1995, the Council proposed to the Union Ministry of Welfare the training of a new group of professionals, called Multipurpose Rehabilitation Workers (MRW). The MRWs will receive 18 months of training and is suggested to be employed at the Taluk level - initially for a population of some 1,00,000 people. The Council proposes that the MRWs will undertake the following tasks:

1. Initiate contact with communities and provide the information requested on the CBR programme.
2. Visit communities to advise them on the practical aspects of the CBR programme.
3. Design, conduct, and evaluate courses to train community workers (facilitators).
4. Assist in the development of multi-sectorial contacts, so disabled people will be involved in mainstream rural development schemes, receive primary health care, education and ability training.
5. Contact referral services, public authorities, or private organisations, regarding disabled people in need of diagnostic, therapeutic or rehabilitation services, and/or opportunities for assessment, schooling, vocational training, jobs, environmental interventions, etc., that cannot be provided at the community level.
6. Monitor all aspects aimed at the legal protection of disabled people to ensure observance of their human rights and adequate representation of the disabled people and their families in all community affairs that are of special interest to them.
7. Ensure appropriate monitoring of the CBR programmes of all communities in the district, and take steps to correct problems that become apparent on monitoring; report monitored information and data to higher levels, and respond to directives aimed at reprogramming or at other changes.
8. Assist, in co-operation with the local and district administrations, with the necessary administrative action to ensure smooth functioning of the programme.

There are other strategies for a service delivery system. It is often proposed to add the responsibilities for disabled people to an already existing category of personnel. For instance health workers or social workers have been used on a part-time basis. This has been tried out in several countries, but unfortunately the experience of this option is rather negative for these reasons:

- the personnel chosen from one sector will most often neglect or even be ignorant of how sectors outside of their own should be engaged to meet the needs of disabled people,
- the training costs are substantially higher, as often 8-10 times more personnel will have to be trained.
- there is most often a lack of clear responsibility and dedication to the holistic approach, which includes wide responsibilities for the rehabilitation programme.
- the personnel will mostly not acquire sufficient experience.

3.2 State activities

The detailed activities to be undertaken by each State includes the initiation of the training and employment of MRWs, and provision of the technical material and administrative support needed by them. State Committees for co-ordination and execution will be set up in accordance with the Act. The State will, as provided for in the Bill, appoint a State Commissioner for Persons with Disabilities with the purposes of promoting and protecting their human rights.

Concerning the training of MRWs and their employment, it is proposed to set up a training centre, that will educate the necessary personnel. This training centre should be located in a place, where the students will have easy access to nearby communities, in which there is an ongoing CBR programme.

3.3 Principles of the service delivery system

A proposal for application of the principles of the CBR sustainable service delivery system in India is shown in Fig. 3 and may be described as follows :

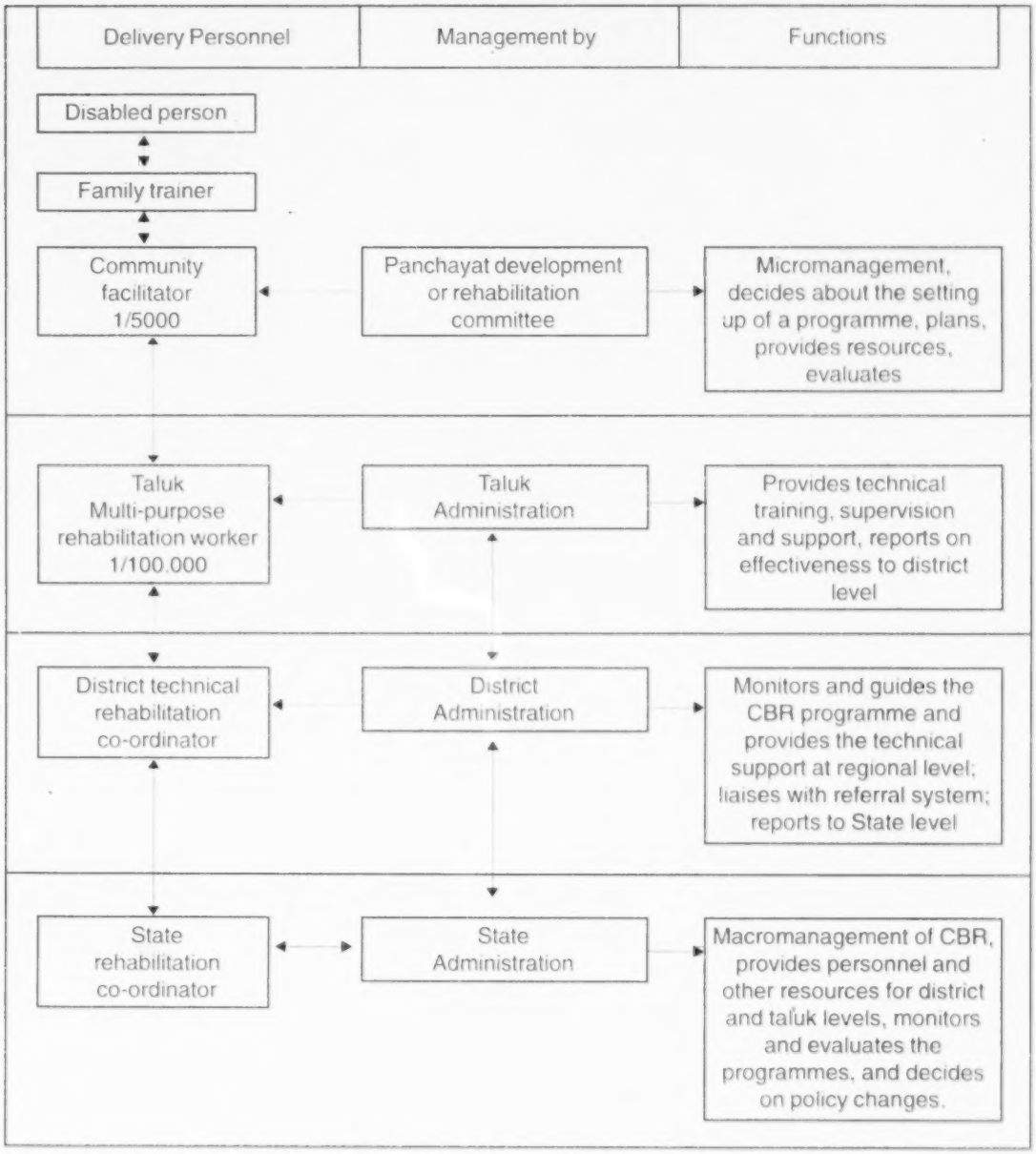
- at the community Panchayat level, the local development committee or a special rehabilitation committee will micromanage the CBR programme. The Committee decides if and when the community will start a CBR programme, what resources to provide (such as employing and training a community facilitator), how to provide access to schemes for functional training, inclusive education, rural development, health, social welfare benefits, care and economic support.
- at the Taluk level the MRW will be responsible for the information to community leaders, to persons with disabilities and their families about disability and what the community can do to provide services and opportunities using already available resources. The MRW will co-operate with personnel at PHC, education, labour, social welfare, rural development, NGOs and others, which will make services available and open opportunities for persons with disabilities.
- at the district level, a district technical rehabilitation officer will monitor and guide the work carried out at more peripheral levels. A report system (for a proposal, see Annex IV) will be set up to serve the State administration.

Members from committee could be sought from among the community leaders, disabled adults and parents of disabled children and other interested people. It should be useful to include such local people, who could contribute to on-the-job-training programmes and employment for those disabled people, who have been prepared for a productive role.

The community leadership should make available and facilitate the inclusion of disabled community members in all rural development schemes. In order to undertake the necessary preparatory process, the CBR system proposes the training and local employment of a community worker, in this document given the title of "Community Facilitator". The training of such a facilitator should be done by the MRW. When it comes to the remuneration (in cash or kind) of the facilitator, each Panchayat should decide how this will be done. It has been suggested that the Panchayat could use part of the rural development funds available to it (at present about Rs. 1,25,000 annually). For instance, the Panchayat may decide to set aside an amount of Rs. 3,000 annually for the facilitator working in a population of some 5,000. The cost at the Panchayat level will in this example amount to about Rs. 60 per disabled person per year.

The State Committees mentioned above will monitor the outcomes of the programme, and based on the results undertake such modifications as will be necessary.

Fig. 3 Delivery system for CBR State level


Delivery Personnel
Management by
Functions
Disabled person
Family trainer
Community facilitator 1/5000
Panchayat development or rehabilitation committee
Micromanagement, decides about the setting up of a programme, plans, provides resources, evaluates
Taluk Multi-purpose rehabilitation worker 1/100.000
Taluk Administration
Provides technical training, supervision and support, reports on effectiveness to district level
District technical rehabilitation co-ordinator
District Administration
Monitors and guides the CBR programme and provides the technical support at regional level; liaises with referral system; reports to State level
State rehabilitation co-ordinator
State Administration
Macromanagement of CBR, provides personnel and other resources for district and taluk levels, monitors and evaluates the programmes, and decides on policy changes.

3.4 Co-operation with Rural Development Schemes

Preliminary discussions have been held about the possibility of seeking matching funds from the Union Ministry of Rural Development. Such contributions could be sought under several of the Jawahar Rozghar Yojana schemes:

a) for training of personnel. The Training scheme has in the past given "extensive support... to a large number of autonomous training and research institutions dealing with issues related to rural development... Training needs are... addressed... through special training programmes, workshops and seminars taken up from time to time... A massive exercise to appropriately empower elected representatives through distance education... is being un-

dertaken in co-operation with the Indira Gandhi National Open University and the National Literacy Mission Authority." These formulations may perhaps allow for funding of the State level training programmes for MRWs, who will then serve as facilitators for the inclusion of people with disabilities in rural development schemes.

b) MPs' local area Development Schemes lists several examples of works that can be taken up, and which could favour the disabled citizens.

c) a number of other schemes for employment, general rural development, housing, training, tool kits, training of rural youth for self-employment, access to capital for small enterprises etc.

In order to make sure that the funds for the gram panchayats arrive without too much delay, it might perhaps be possible to suggest that each community setting up the CBR programme gets an incentive of Rs. 1 per inhabitant.

4. Phases in the development of a CBR programme

It may be suggested to follow a stepwise development of State CBR programmes. These could be :

Phases 1 : Setting-up of a development project, e.g. for 10,000 to 20,000 people. For this purpose, some rehabilitation professionals will be needed, they should be prepared by training in an existing successful CBR programme, e.g. in Karnataka, for a period of 3-4 months.

Upon their return, they could start CBR activities in an area where the population is interested and that lies close to the proposed site for a future Training Centre for MRWs.

After 1-2 years follows :

Phases 2: Training of a group of MRWs for 18 months using the development programme and in accordance with the Rehabilitation Council plan.

Phases 3: At the end of the course, the MRWs will be placed on the taluk level and employed.

Phases 4: The MRWs will meet with the local Panchayats and present the programme. If the Panchayats decide positively about their involvement in and contribution to the programme, a community worker (facilitator) will be trained (for about 10 weeks by modules of 1-2 weeks).

Phases 5: Community workers start delivering services.

Phases 6: MRW provides supervision and liaison with referral services and other contacts.

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AN OVERVIEW OF CBR IN PRACTICE IN INDIA

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Dates of Actual Presentation : 31.3.97 - 4.4.97

Introduction

During the eighties, there were major changes in attitude towards disabled people all over the world. The most important of these changes culminated in the decision by most of the world bodies to develop rehabilitation of disabled people as a special thrust area. This decision gave rise to 2 major streams of activity. One was the effort by groups of disabled people in the "Independent Living Movement" to gain control of management of rehabilitation programmes from the professionals. This form of empowerment became the vogue in developed countries. The second type of activity was concerned with the setting up of service systems for disabled people in developing countries, who are the poorest of the poor and who had hitherto been ignored even by agencies who worked for poverty alleviation. There were very few options to develop a service system in these countries, since no attempts had been made to rehabilitation large number of disabled people living in rural areas till then. A new service system called "community based rehabilitation" (CBR) has since been developed, where the attempt is to shift rehabilitation interventions from institutions to the homes of disabled people, to be carried out by minimally trained non-professional persons in the community. Attempts are made to achieve an optimum quality of services at an affordable cost, keeping in mind that the quality of interventions introduced through CBR should be better than existing traditional methods of rehabilitation. It is considered important that the communities who benefit from these services should gradually take over the services and that disabled people should have a say in planning, managing and monitoring of the programmes.

During the eighties and early nineties, many small CBR projects came up in different developing countries, based on CBR principles. India was one of these countries. The ACTIONAID-India, Disability Division is a major promoter of such CBR projects in India, and has been experimenting with different methods of interventions. Today, the ACTIONAID-India Disability Division has access to one of the largest sets to small CBR projects in a single country.

In the mid-nineties, the focus is shifting from developing small projects, to coverage of entire countries, i.e. national level planning. The skills needed for this kind of planning are different and not easily available.

An overview of CBR programme in India

Development of CBR programmes will be with much faster pace with the availability of minimum infrastructure in any given area. Hence, Southern part of our country was able to implement most CBR projects as the infrastructures of Health, Education, Training and Employment are well developed and functioning.

At present more than 20 CBR projects are functioning in the 4 States. Each of these projects have some similarities and some differences. Objectives, structure, programme components of the project, type and category of target group being served, training and background of grass roots level workers are most common among all projects. Whereas, the approaches followed to achieve the objectives, do vary to a greater extent.

Objectives of all projects is to provide rehabilitation services to the needy disabled persons in a given area so as to improve their quality of life. In fact, very few projects looks at empowerment

of disabled people to manage rehabilitation services by themselves. A few others purely aim at shifting the rehabilitation services from institutions to the periphery.

Structures followed by most CBR projects are of the 3 tier system. Policy level consisting of managers who plan and manage the projects, a band of mid-level staff who have acquired technical skills required to be transferred to the community and a large number of grass roots level workers who act as change agents in the community. A small proportion of projects also have the 4th level of community drawn paid or unpaid volunteers to support at the village level.

Managers of CBR programmes are mostly from the disability rehabilitation background either suitably qualified or with rich experience from an institution. It would be ideal to have persons with expertise in both technical and managerial skills to manage the CBR projects. Training and Research Centre for Rehabilitation (TRCR), Madanapalle, India, offers one month course for CBR Managers. Another course for managers is held at Institute of Child Health in London.

The second level of mid-level staff are generally supervisors or co-ordinators who would monitor the programme in a given block of cluster of villages, also they possess higher managerial skills and develop community rapport. Some of the projects assign the sectoral responsibilities to this cadre of staff, for e.g.; Health specialist, education specialist, economic programme specialists etc., The group of staff comprising of technical team having part-time or full-time therapists/professionals in each area of disability and a set of multipurpose therapy assistants (MPTA) and technicians who work under the supervision of professionals. MPTAs provide therapy inputs on a regulars basis to grass roots staff and parents of the disabled persons and periodically get themselves trained for higher skills from the professionals.

Technicians specialized in orthosis and prosthesis will repair and maintain the aids and appliances also transfer the skills required for simple maintenance and better usage of aids and appliances. Most projects having orthotic and prosthetic workshop or aids and appliances manufacturing centre will train technicians needed for CBR projects. Generally, a community drawn persons with mild or moderate locomotor disability would be trained for this purpose.

The responsibility of implementing most of the programme activities lies with the grass roots level workers. Usually, they are selected from the same community and are with a minimum qualification of 10 or 10+. Mixed proportion of sex ratio would be ideal, as it is felt that the female workers would do better in family counselling and dealing with mothers and disabled women whereas the male workers would increase coverage and also found to be better organisers at the community level. It would be ideal if the grass roots workers stay within the community and undertake minimum travel to reach their target villages. They are the link agents between all the available resources and the disabled persons. Effective training inputs in the areas of both technical and managerial skills will strengthen the programme activities. It is essential to provide demystified ongoing training for the grass roots staff as they inturn train the persons with disabilities and their family members. Simple exercises of therapy, activities of daily living skills, conducting awareness programmes, organising at the village level, liason with local authorities, local resource person for health, education, training and employment needs of the disabled persons, are the major roles carried out by the grass roots level workers.

Some projects, do have Community Rehabilitation Volunteers (CRV) for every village or couple of villages who are minimally trained, generally devotes 4-5 hours a day for rehabilitation programmes. The CRVs are mostly effective as grass root organisers, but technical inputs would be difficult. However, 3 out of the 4 projects having CBRVs at the grass root have failed to achieve its objectives in the desired manner. This is largely due to dilution of efforts while transferring skills from the professionals to the consumer. Secondly, the CRVs are generally low paid part time staff (Rs. 300-400 per month) and hence rehabilitation will be secondary for them.

Programme Component

Most projects has the restorative, preventive and empowerment related activities as part of the programme components. Health and Medical rehabilitation, Education and economic programmes are under restorative measures. These are specific interventions directly related to individual disabled persons and their families. Prevention, Nutrition and Awareness building programmes in collaboration with the existing health and community development infrastructures form the support services of CBR projects. These are mostly non-specific in nature and are more directed towards the community at large.

The concept of empowerment of disabled is still in a premature stage. Projects and disabled persons are not still convinced that they will be able to manage the programmes themselves. However, a few projects looks at this part in great detail. These project also believe that Group organisation, group savings and credit programmes, Self-help-group formation and transfer of technical and managerial skills to these groups, awareness towards attitudinal changes in the community, influencing policy and advocacy and concentrated internal and external fund raising programmes would lead to empowerment of persons with disability. Experiences of these projects at this stage are quite promising.

Approaches

This is an area, where most projects vary from one another. Approach to achieve the global objectives in CBR depends on the basic philosophy followed by the implementing agency, type and degree of disability being served, socio-economic status of the community, presence and functional level of infrastructures of rehabilitation. It is a continuum on which major two distinct approaches are experimented. Creating service provision for the target group is on one side and preparation of the community to manage CBR programme is on the other end of the continuum. It is still not clear about what is the best proportion of these two issues to be focused while initiating a CBR programme.

Examples of 4 different models existing in India are discussed in this section: namely; DRC model, AAI model, ADD model and Seva-in-Action model.

The DRC model

Almost parallel to NGO CBR initiatives, the Govt. of India launched District Rehabilitation Centre scheme on pilot basis in 1985. It has a 3 tier structure-village level, PHC-level and District-level. At the village-level, there is a village rehabilitation worker (VRW) at the rate of one per 1000 population. A cluster of villages having a population of about 30000 has a Multipurpose Rehabilitation Assistant (MRA). The next tier is at the PHC level and is known as PHCRU. The PHCRU is headed by the Medical officer in charge of the PHC who is overall in charge of all the activities in the area covered by the PHC. He is assisted by two other staff namely, the Multipurpose Rehabilitation Therapist (MRT) and Multipurpose Rehabilitation Technician (MRTecn). At the district level is the District Rehabilitation Unit with the District Rehabilitation Officer (DRO) as the head who is responsible for the achievements of the objectives of the scheme in the district.

This is the govt. top-down model with no community participation efforts. Hence, the evaluation after 10 years of interventions revealed that the progress achieved was only under the Health component. There was a large gap between the community and the DRC. In fact DRC staff were waiting for the disabled persons to visit DRC and get services and on the other hand, the disabled persons were not aware of DRC. However, this model has generated interest and helped national level planning for implementing CBR country wide. This model has the advantage of coverage at a faster pace and easy to implement, monitor and evaluate.

The ACTIONAID INDIA Model

The AAI model emerges as a result of series of 17 micro CBR projects initiated in different parts of the country. Learnings from these projects were valuable as these projects were funded and monitored by a single agency from a single office. Hence, AAI takes credit of having access to a largest set of CBR projects in a single country.

The nature of its structure and programme components have been discussed in the earlier part of this paper. This model though appeared to be top-down in the initial stages, there are significant efforts by these projects to increase community participation level. ACTIONAID believed in initiating CBR programmes through the existing institutions working for the upliftment of persons with disabilities, instead of replacing institution based programmes. This helped CBR to be supported by them as the resource base. The institutions were motivated and their capacities were enhanced to initiate CBR programmes mostly in rural areas and urban slums. Amongst all the projects, service provision to the disabled persons, family members, and enhancing capacities within the community to meet the minimum needs of rehabilitation was the focus.

At present most of these projects are working towards preparing the disabled people and the community to gain control over management of the CBR programme. This model believed in the concept that the rehabilitation is the last priority in any community and hence, the projects need to establish rapport and demonstrate positive results of rehabilitation to the community members. This process takes about 2-3 years and later the project tries to involve the community actively in its planning, monitoring, managing and evaluation process. Over the years projects were geared to achieve the overall goal to empower people with disabilities. In the sense, people with disabilities along with the local community support be able to manage the rehabilitation programmes. Each project was given freedom to choose the appropriate approach with flexibility to change during the mid-course. Required financial, technical and human resource support extended and were closely monitored by AA professionals.

Learnings from this model :

Prevalence study :

Identification of persons with disabilities and needs assessment study was conducted during 1992-93 in 12 ACTIONAID supported CBR projects. The total population covered was 12,87,114. The tools were developed by the project personnel themselves with the help of minimal external support. Volunteers were used after brief training, to collect the data from the house holds. Pilot studies were undertaken before the final survey. Results of the study were as follows:

- Locomotor disability is the most common disability identified (0.63%) which amounts to 1/3rd of the total disabled persons identified. About half of them are below 30 years of age. Followed by visual disability, communication disability and mental retardation.
- The average prevalence rate for all projects was 1.690% for the entire population, while it was 1.622% when only the population below 30 years was considered.

Mid-term Evaluation :

10 CBR projects undertook mid-term evaluation during 1993-95 and the results brought out both positive and negative issues as part of the self-learning process. On the positive side, the evaluation has reported minor to significant changes in disabled persons covered by the programme such as increased awareness about disabled people, their problems and potentials, improvement in mobility, social activity skills, increase in confidence of the children and

parents and income enhancement of disabled people after rehabilitation. On the negative side, however, there is less satisfaction among those afflicted with severe and profound disabilities. This model operates through established voluntary organizations. In most part of the country, voluntary organizations of this kind or of any kind do not exist. Almost, all the ACTIONAID's projects are located in the urban areas or in the rural areas close to the urban areas. The replicability of the model therefore throughout the country is doubtful and difficult.

Future perspective :

With the experience of programme development in CBR the disability work in ACTIONAID-India is entering the new phase from 1997 with the objective of integrating disability programmes into its development initiatives; apart from continuing its renewed focus on current activities. It is planned to initiate this phase with the sensitization and capacity building of ACTIONAID's 7 regions. 2 pilot projects have been initiated in Gwalior and Mysore districts which aims at integrating CBR into their existing Health and Rural Development programmes. Both these initiatives, have the horizontal structure existing and working in the target community. The CBR programme components will be integrated with the existing structure through their capacity building and the project will have a technical support team. ACTIONAID awaits to share its Learnings which could be indicators for a national programme on disability rehabilitation.

THE ADD - INDIA MODEL

ADD - India was another pioneer organization in this country to establish their philosophy of Empowerment model. ADD India believes in the empowerment of disabled people and the community right from the word go. This model is considered to be the most effective and sustainable model for developing countries. The approach will be totally bottom-up having strict horizontal structure. Virtually, the role of the project is to facilitate in the community during the process of empowerment. In other words, a single (preferably disabled) person who will be fully trained in the aspects of rehabilitation and community organisation will get into the community. His/her role is to motivate and activate the community about their responsibilities with regard to rehabilitation. Disabled persons will be motivated about their rights and privileges. They will also be trained to form a group, popularly known as self-help groups to work as pressure group within the community and demand their rights with the local, regional and State Government to gain access to existing facilities health, education, training and employment opportunities.

ADD emphasize rehabilitation as the integral part of community development programme. Hence, under this model, service provision directly by the project is the last priority, also this model believes that the service provision to disabled persons or family, creates dependency on the project and hence the programme will not sustain after the withdrawal. Typically it is referred to as dependency syndrome.

This model appears to be the right model for the countries having scarce resources. But, it is extremely uncertain to achieve this objective of preparing a highly motivated / active community volunteers to spare their own resources, initially for a better tomorrow. Generally, community people in developing countries have greater expectations of short term goals relating to their immediate needs rather than working towards sustaining a non-existent programme. Rehabilitation per se involves long term interventions to achieve smaller changes in quality of life of disabled people. Hence, it is difficult to convince people to participate in rehabilitation programme without demonstrating any direct benefits them. Hence, this model has the greatest disadvantage being a very slow process. This also might lead to frequent failure of the programme and some times the project may not take-off itself.

SEVA-IN-ACTION MODEL

Seva-in-Action being one of the pioneer organizations in initiating CBR programmes in the country has shared its expertise and Learnings towards development of this field. This model was based on creating CBR committees at the grass roots level managed by the local key personnel. A community member will be trained suitably for the purposes of rehabilitation. The cost of rehabilitation will be raised by the CBR committee through local resources, local govt. and donors. This would involve a nominal salary for the local volunteer. This model has tried to spread the message of CBR as the committees are community based in real senses. Also, the ownership of rehabilitation lies within the community and the members are involved in planning, managing, monitoring and evaluating the programme.

Lessons learnt over the last 2 decades from this model are, that the selection of community volunteer becomes difficult, generally highly committed persons only can work for a nominal salary. CBR committees slowly disintegrates as the members do not have any direct benefit for their participation. Local politics such as social hierarchy, power dynamics takes the major role. Rehabilitation will be restricted to only referral system rather than provision of comprehensive services. Hence, only the affordable person could get the better form of services. This model was tried only in small towns but a large proportion of disabled people live in villages.

CONCLUSION

To conclude, no single plan is totally relevant to a particular place or time or context. What is best in one can be worst in another. All plans/models have positive and negative dimensions. It is important for the CBR promoters to include the most appropriate dimensions in their plan in relation to their context, and also to ensure that the programme being planned will in some way be better than what previously existed.

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SAMBHAV - CBR Linkage Model of Early Intervention by The Spastics Society of Tamilnadu.

A. Introduction

Traditionally Rehabilitation services for Disabled persons in India have been both Urban-based as well as Institution-based. It is estimated that in 40 years of Rehabilitation services only 2% of the Disabled population in India have been reached, either by services or by information. 98% of persons with disability have had neither any knowledge of the existence of these services nor, of the benefits to be derived thereof.

B. The need for CBR

From the mid-80s, Planners and professionals had begin to accept the limitations of this traditional Institution Based Rehabilitation (or IBR) approach, when applied to a large, diverse, economically marginalised and predominantly rural population like India's. Different options for increasing coverage have been discussed at length and Community Based Rehabilitation or CBR appeared to be the most reach-effective, more cost-effective and the most likely to achieve inclusion of disabled persons in their own Communities.

This inclusion, or integration, is certainly the primary goal of all Rehabilitation efforts on a global basis.

C. About SPASTN - IBR

The Spastics Society of Tamilnadu (or SPASTN) has become working in the field of Rehabilitation from 1981. It operates through a continuum of services which includes Awareness Creation, Prevention, Early Detection, Early Intervention, Special Education, Physiotherapy, Pre-vocational, Vocational Training, Job Placement, Manpower Development, Material Development, Research, Making of Aids & Appliances, Advocacy, School Integration etc.

Upto 1990, SPASTN's approach in this wide-ranging service delivery system was a purely Institution-based one, through 3 multifunctional special education centres in the South, Central and North Madras areas.

i. Organisational Change :

Outreach

In 1990, the expressed needs of our outstation parents from many other districts in Tamilnadu and from the neighbouring States of Andhra Pradesh, Madhya Pradesh and Union Territory of Pondicherry, prompted us to extend our services on an outreach basis to these places.

ii. Community Based Rehabilitation :

This is the story of Project DARC, Disability Awareness and Rehabilitation in the Community, a CBR programme of The Spastics Society of Tamilnadu - a programme which is essentially a response to the felt and expressed needs of families of children with disabilities. It is also a programme which directly addresses the subject of Networking which I have been asked to speak on.

DARC is a Linkage Model of CBR in Early Intervention with the Community, the Integrated Child Development Scheme and the Primary Health Centres as its main partners linked together for the singular purpose of preventing, detecting and managing childhood disabilities within the community setting. DARC primarily serves the 0-6 yrs. age group, with special emphasis on the high risk newborn baby, i.e. the low birth weight baby, the premature baby, the birth asphyxiated baby and a few other babies who are at risk of acquiring disabilities or developmental delays. This is perhaps the only model in India where the Health and Welfare sectors have come together on a common platform to share resources and skills at the community level.

The house of DARC Built with Multi-sectorial Pillars :

The house of DARC is built on 6 Pillars, with the community as the foundation. Pillar one is Awareness Creation, Pillar 2 is Screening and Detection in hospitals, in balwadis and schools, and through camps. Pillar 3 is Early Intervention on a multi-site basis, Pillar 4, is Training of GRW and Pillar 5 is Referral Chain. Pillar 6 is Cross-sectorial networking.

iii. Mobile Van :

Some of these monthly Outreach or Extension services of SPASTN caught the imagination and the interest of the local communities and blossomed into full fledged Community Based Rehabilitation services for disabled children on a daily basis.

iv. Sustainability - Networking is a Need, not an option :

This is perhaps the most crucial aspect of Project DARC - the utilization of, and merging into, the facilities, programmes and schemes that are already existing in the communities. This is where the ultimate question of sustainability of any CBR programme is tested, and we have built it in from the earliest stages of Project DARC. Within one year of its inception, DARC has merged permanently into the existing infrastructure of the ICDS and the PHC and become part of the routine activities of the community.

Although DARCs primary involvement-group is the 0-6 yrs age group, it goes without saying that all ages, and all disabilities have become integrated into this CBR programme. Older children and adults have been involved through efforts in school integration, some through vocational training, some through job placement and yet others through the fitting of aids and appliances like calipers, crutches, wheelchairs and tricycles which have enhanced their mobility and independence. Community involvement, apart from the health and welfare workers, have been through disabled persons and their families, schools, religious organisations, fraternities like Mahila Mandals and youth clubs. Wherever they have taken over the responsibilities for Rehabilitation services, that this where inclusion and integration efforts have been best served. This is especially so where Disabled persons have taken the lead in Rehabilitation.

In the ultimate analysis, SPASTN's role here is that of a catalyst, an agent of change. Whenever there have been a demand for services, SPASTN has responded with Outreach services extended from the 3 urban centres. These outreaches have evolved in some instances into nodal CBR programmes. As each CBR programme has become strengthened, they in turn have capped their achievement by starting outreach programmes of their own, which too will one day become nodal centres in their own right. Thus, a rippling effect will be created, until first the whole district, and later, the whole state and neighbouring states are covered through Rehabilitation services for, by, and of, persons with disabilities.

HORIZONTAL MODEL O *F*CBR

This CBR model is more cost effective firstly because it is supported by community resources, both in manpower and in material ways. Secondly, it has not sought to set up a whole new, and expensive infrastructure, rather it has utilised and converged into infrastructure that already exists in the community and strengthened their capacity to include and integrate issues, options, and services in Rehabilitation.

Objectives / Activities of DARC :

1. Prevention

The objectives of DARC and its concretization into activities are very clear - it seeks first to prevent disabling conditions through greater public awareness and education. What is to be emphasised in these direct contact awareness programmes apart from general preventive measures, is the importance of nutrition and care in the prenatal and postnatal periods - a sort of "do's and don'ts" of pregnancies. Simultaneously knowledge about Disability and the abilities of Disabled persons is disseminated. Superstitions and myths and fears about Disability are sought to be dispelled. This has helped to create greater acceptance of Disabled persons and an understanding of the need for Rehabilitation Services. Equally important we believe, is to create a more positive environment in the community in favour of Disabled persons. So the parallel objective of Public Awareness Creation is to effect attitudinal changes within the communities. An entire cross-section, of society is reached - young adults in schools and colleges, mahila mandals, youth clubs, village and peri-urban community people, professionals, the medical fraternity and personnel of different government and non-governmental organisations already working in the communities.

A direct effort in Primary Prevention is the provision of Paediatric Ambu Bags to the PHCs with which SPASTN is connected. The Artificial Manual Bagging Unit provides better management of birth asphyxia at the PHC premises itself and helps prevent adverse effects which could include cerebral palsy and mental retardation in many newborn babies. Without this simple equipment these aphyxiated newborns have to be sent to the District-hospitals, several hours away, by which time brain damage will have already taken place.

2. Early Detection

The second objectives and activity is early detection, as early as possible, sometimes before birth, through monitoring of high risk pregnancies at the Prenatal clinics in Government Hospitals. High risk pregnancies include those with attempted abortion, a history of still births, diabetes, hypertension etc. and of course those with a family history of disabilities.

The other major strategy for realising the objective of Early Detection is to screen newborn babies within 3/4 Days after birth. This is implemented at 12 Primary Health Centres and one First Referral Unit. In each of these health centres, nurses are being trained simultaneously for sustaining SPASTN's early detection efforts. This nonmedical newborn screening is more like a developmental surveillance where highrisk newborns are detected, intervened with and monitored for 6 months. If sensory stimulation and proper positioning is provided at the neonatal stage along with competence building efforts of parents, the developmental outcome of these babies is likely to be very much better. This is also a form of secondary prevention.

Screening is continued beyond the newborn stage to the infant and early childhood stages, through the regular services of the PHCs, through Balwadi screening and through participation in and organisation of Health CAMPS, where SPASTN comes in with the Disability input.

3. Early Intervention

The third major objective of DARC is the provision of early intervention services. This is through a holistic and eclectic intervention which includes physical therapy, communication therapy, special education, Adolescent Training and self help skills. Its important to reiterate that the mother and child are seen here as one unit.

Indeed, the partnership between parents and professionals is the cornerstone of any successful early intervention programme, anywhere in the world. And in the rural and remote villages of India, where transportation for parents is as big a problem as paucity of trained professionals, this parent - professional partnership forms a solid foundation for the child's development.

This same problem of long distances and limited manpower has inspired multi-site service delivery options, which include the child's home, or a local patrons home for group work, a room in a local school, or in the local church or even in the local PHC. Some of these intervention sites operate on a daily basis, some weekly and some are outreach programmes which operate on a monthly basis. Early Intervention must be seen here as a measure in tertiary prevention.

4. Grassroots Workers Training - Networking Practise

The next major objective cum activity is perhaps the most imperative for the sustainability of the DARC, or of any CBR programmes for that matter. This concerns the transfer of knowledge about disability and skills in Rehabilitation to the community. The curriculum is designed to include knowledge about all disabilities, both for early detection and for early intervention with a very heavy input on Prevention. WHO described CBR as a "democratization of Rehabilitation."

SPASTN's conscious efforts to demystify knowledge and skills in Disability has helped a great deal in the democratization of Rehabilitation and the empowerment of the local people. However, it is necessary to emphasize that this training recognises the importance of a continuum of professional competence in CBR.

The staff of DARC have been involved in this structural transfer of skills from the very beginning on a three-tier basis.

DARC Staff	To parents and to disabled people
	To the staff of ICDS, which includes Anganwadi workers level I and II, Supervisors and CDPOs (Child Development Programme Officer)
	To the health workers - village health nurses, Community Health Nurses & Sector Health Nurses.

Apart from these groups in Chengelpet District SPASTN is also training Special Teams and Mobile Teams in Pudukottai and Nilgiris Districts.

Appropriate Paper Based Technology :

An important part of the training is A-P-T (Appropriate Paper Based Technology). This is a technique with which special furniture and therapy equipment can be made at NO cost at all from used cardboard, paper and flour. This strong and sturdy aids are particularly applicable for Indian conditions.

Health and welfare workers, as well as parents and disabled persons are encouraged to make use of this technology for their own homes and for their balwadis.

In fact the development of Low Cost Aids as well as the use of consensus Technology is vital for the success and survival of any, rural CBR programmes in India. We have emulated

David Werners' model and made these parallel bars, prone boards, balance boards and hammocks from used tyres and bamboo. This play cum therapy equipment has been made by the parents of some children with disabilities. This play ground is used by non-disabled children also and goes a long way towards integration of children with disabilities.

This equipment which is essentially a corner seat and a standing tolerance frame is made from mud and waste material in the child's home. It serves the same purpose as expensive wooden equipment but is infinitely more financially accessible to the families that we work with.

We have tried to incorporate the 4 Principle of technology for CBR - that they be appropriate, accessible, affordable and available to those who need it most. Therefore, whenever possible local resources and local manpower has been utilized.

Most disabled children, especially in infancy and early childhood, benefit from orthotic devices. SPASTN already has a fully equipped Core Workshop and orthotic section in its Head Office in Taramani, Madras. For the DARC project, the Orthotics visit on a weekly basis, assessing the individual child's specific needs and measurements and devising innovate and indigenously made aids and appliances which enhance independence on the one hand and which prevent contractures and deformities on the other.

To facilitate the awareness and the training programmes, a great deal of training and awareness creation material has been developed in consultation with the community workers. These include Posters and Screeners on Early Detection, Brochures on Prevention, Booklets for Parents and an exhaustive Manual and Video Cassettes for Community Workers. The material is illustrated and the language used is simple Tamil.

Project DARC has generated a lot of data in the 2 1/2 years that it has been operating as a full fledged CBR programme. What is evident from this data, is that, whereas the incidence of polio and leprosy is on the decline, the incidence of multiple disability is definitely on the increase. Part of the reason for this is that many high risk newborns, who were earlier dying, are now surviving traumatic newborn insults because of better medical care. These fragile babies are most vulnerable for brain damage and likely to be in need of Rehabilitation measures at a later date.

Whatever be the reason for this increase, we are now in a situation where the demand for special services for children with multiple disabilities are multiplying every day. From a CBR approach, this group poses the greatest challenge. That is probably why, on a national scale, almost no CBR programmes have addressed their needs so far in an ongoing, regular and large-scale manner.

D. Referral Services - Benefits of Networking :

Any CBR programme will usually address about 70% of all the needs of Disabled persons at the community level. The balance 30% would need to be referred elsewhere and this is one of the reasons why this Linkage Model has proved to be effective. Because of the strong partnerships forged between the Government programmes and an NGO, the onward and cross referral for other services like medical and vocational intervention is more easily facilitated.

E. CBR Model :

While the concept of CBR is universally applicable, each CBR model must be uniquely tailored to suit the needs of individual communities. Since communities differ with regard to availability of resources, economic status and social attitudes, adaptations and modifications are necessary. What can be replicated is the broad model, which is what DARC, aspires to be, universal in concept but specific in application.

F. ID-Interface on Disability - NGO Network :

The present effort is an attempt to link existing NGO efforts in every District in Tamilnadu. The aim is to build the capacity of these NGOs in Early Detection and Early Intervention so that they can function as Nodal Centres for their Districts. They in turn are training existing Village level workers in Welfare and Health so that ultimately every village in Tamilnadu will be covered, in terms of disabled children in the age of 0-6 yrs.

G. Conclusion :

In the final analysis and in the growing realisation that Rehabilitation as we have known it for the past 40 years, is not reaching those most in need, there is a clear understanding that Networking, Linkages, and Convergence of Rehabilitation efforts not only has a great potential, but indeed it is the only possible strategy for a developing country.

David Phaxton of UNICEF has said "Nothing is costlier to the Nation-especially a low - income country-that to allow a child to be exposed to the risk physical or other impairment, let is escalate into an irreversible disability and then to look for resources for rehabilitation that can never be adequate."

It is worthwhile to repeat that in this context, Networking and CBR is not an option, it is an imperative.

CBR FACT SHEET

Dear CBR Fact Sheet Reader,

This is a CBR Fact Sheet on IED. The purpose of this publication is to facilitate massive dissemination of information on Integrated Education of Disabled Children, through CBR Networking in south Asia.

This Fact Sheet will make an attempt to present :

- Meaning
- Genesis
- Implementation, Different strategies
- Prerequisites
- Advantages
- New Perspectives.

What is IED? (Integrated Education of Disabled) IED means, Education of Disabled Children in a least restrictive environment, along with their normal peers in a regular school setting, so that they develop like other children.

- Prof. N.K. Jangira, National Council for educational Training and research (NCERT) says Integration is the process of bringing of the "part" (i.e. children with Disabilities) to the whole society.
- Integrated Education is a supportive education given to children with a special need(s) in a regular school setting in order to achieve the goals of Universalization of elementary education.

Genesis of I.E.D.

- Education is one of the essential inputs to ensure the quality of life of an individual. Hence the right to education has found significant place in all the constitutions. Universalisation of Education has gained momentum over the past two decades in South Asian region.
- The National Policy on Education of 1986 in India, has laid special emphasis on the removal of disparities by creating equal educational opportunities for children with special needs in regular schools.

Who implements IED?

Integrated Education of Disabled as it exists, can take place in two different ways :

a) **INCIDENTAL INTEGRATION** is a situation where, children with special needs are enrolled to fulfill the goals of compulsory enrollment Children with mild visual / hearing difficulties and with physical disabilities are admitted. This is partly because the sensory disability is not visible and physical disability is not seen as a problem by teachers.

b) NGOs / voluntary organizations and governments are implementing IED as a centrally sponsored project in India.

IED strategies

a) **Regular Class room model:** Disabled Children are "taught" by general teachers in a regular Class room.

b) **Curriculum adaptation:** The general curriculum is adapted and modified to suit individual needs of children with disabilities. This is evolved by regular teachers by experience and interest (this is very rarely seen).

c) **IED Setting with Resource teaching facilities:** Additional time is spent in the resource

room where the resource teacher provides special help for specific learning problems of each disabled child. The resource teachers are peripatetic and give support to a cluster of schools. The resource teacher also helps classroom teacher in adaptations and modification in the curriculum, teaching methods etc.

The Itinerant Resource Teacher :- Who visits and provides special education service for a group of Disabled Children in a cluster of schools.

d) **Special Class in a Regular School :** Full time self contained special class within regular school premises, where children are integrated for open curricular activities.

e) **Integration after Preparation through self help groups (in CBR) or in special schools :** Children are integrated after preparation in basic skills in cognition, language \ communication, self help socialization, motor.

Pre requisites for IED

a) Early identification of disabilities among children in regular schools and in the Community.

b) Preparation of school authorities, regular teachers and students on the need and philosophy for IED, and to ensure their positive attitude.

c) Community awareness of IED.

A Resource Room with appropriate learning materials teaching aids and materials for cross disability groups of children with varying degrees of difficulties in learning.

Advantages of IED

a) integrated Education envisages low capital investment (expenditure on setting up separate infrastructures)

b) It is most conducive for social and psychological integration

c) Negative attitudes towards Disabled Children are reduced. Facilities a natural acceptance by peer groups.

d) There is scope for an over all improvement in the quality of teaching in general schools, depending on initiatives of both the regular teacher and the resource teacher.

New Perspectives

The UNESCO at the world Conference in 1994 in Spain on Special needs Education, which attracted more than 300 participants representing 92 Governments and 29 International Organisations, provided a forum for reviewing and discussing means by which schools can better serve the training and educational needs of all children, particularly those with special needs, and a framework for Action was involved.

a) They observe, that education of children with special needs is an issue of concern to all countries and it cannot advance effectively in isolation, from other educational services.

b) Special Needs Education as mostly aptly said, must be and integral part of both an over all Educational strategy and social and educational policies.

c) New thinking in Special needs Education: introduced by the director general of UNESCO Dr. Frederico May recommendations were made in framework for Action in 5 sectors viz:

1. On School factors, 2. Training of teachers, Counselor, etc. 3. Links with CBR, 4. Community perspectives, 5. Public Policies and legislations supportive to IED.

d) The World Conference urged in their final statement, that all Governments to" adopt as a matter of law or policy, the principles of inclusive Education, for enrolling all children in regular schools unless there are compelling reasons for doing otherwise".

e) The full inclusion of all children in ordinary schools can come about only as a result of a reform of the school and of the education system as a whole . It is the whole education system and not just one aspect of it that should be reformed to make inclusive Education possible.

Ture Johnson, UNDP, Disability Action Programme Geneva, & former Advisor on Special education, UNESCO, says the two terms **inclusive and integrated Education** sometimes sound confusing.

Hence he argues, the need for using the term **inclusive education? He** explains that "in order to speak about integration there must first be segregation. It is some kind of a repair concept; something that we have done wrong and now want to correct the future. We want people with disabilities to be included from the beginning. Hence the term **"inclusive" education** preferable.

For more information on inclusive education write to CBR Network.

Partnership market news.....

OF-0018 : National & provincial (state Level) CBR Plan for the governments

OF-0019 : Multipurpose rehabilitation Workers Training curriculum (18 months)

OF-0020 : Local CBR Facilitators curriculum (12 weeks)

OF-0021 : Training of Trainers in Logical Framework Analysis (LFA)

OF-0022 : Planning inclusive education for Children with disabilities-Plan of Action.

OF-0023 : How to start Self Help groups in CBR.

OF-0024 : Curriculum for Multicategory teachers training for Integrated education.

OF-0025 : Curriculum on IED for integration into teachers training curriculum.

(Please send your requests to :

CBR NETWORK, Bangalore) See below for the address

OF-002 : P.G. Diploma in Special education for persons with Disability (senior)

OF-0027 : Special education for children with cerebral palsy (Junior)

OF-0028 : Basic Developmental Therapy course for children with cerebral palsy

(The Training programmes offered by Spastic Society, Tamil Nadu is recognised by Rehab Council of India)

Contact :
Mrs. Aloka Guha,
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Self Help groups / Mutual / Support Groups For Adults with disability in CBR programmes

Guidelines Prepared by CBR Network
NETWORK - South Asia

Preamble :

The purpose of any CBR programme is to empower people with disabilities. The process of empowerment of adults with disability and

families with a member with Mental Handicap essentially depends on well defined plans and strategies to promote and sustain Self Help Groups in their own communities.

The Advocacy Groups are by and large urban based. But in reality, more than 80% of people with Disabilities live in rural areas. That is why we need Self Help Groups in rural areas.

What is empowerment :

Empowerment is an ongoing process which enables an individual to fulfill his duties, responsibilities and protect her/his rights in the society.

CBR and empowerment :

Empowerment of people with disabilities is the Ultimate goal of any CBR program. The road to empowerment compels the community to create and promote equal opportunities so that people with disabilities get an access to:

Health Services, Education, Housing facilities, Work placements, Emotional Security, Family bonds, Marriage, Leisure/free personal time, Recreation and other needs. And above all, the right to choose - Full participation in decision-making on, issues concerning self, family, community. Self Help (Mutual support Groups of people with Disabilities) Self Help Groups provide a forum for people with disabilities in rural \ tribal areas.

The objectives of Self Help Groups (mutual support groups of people with disabilities) are :

1. To provide a forum for sharing experiences and identification of needs concerning the individual and the community. It identifies strength and abilities and builds on them.
2. To act as a Nodal Organization to meet the immediate needs of Adults with disability.
3. To facilitate mutual support in times of crisis.
4. To promote self and group advocacy and networks with other advocacy groups.

How to promote Self Help Groups in CBR programs :

1. Start in a known village.
2. Discuss with Adults with disability (above 16 years)
   a) what is Self Help Group ?
   b) the need to start Self Help Groups
   c) and explain the objectives of Self Help Group
3. Let the group meet once a week at a place convenient which could be one of the homes of a disabled member. Let the group identify a facilitator for arranging meetings, sending information, documenting the proceedings etc.
4. Organize together with them First Level Leaders Advancement Workshop for all members with disability.

5. Let the group identify and classify the needs and problems into - individual, family and problems which are common to all Disabled people in the entire village.

   It is necessary in south Asianian context for Women with disabilities to meet exclusively and join the general group once a week.

   (The frequency of the meetings : Weekly Self Help Group meetings is ideal).

6. Strategic plans to meet the needs should be planned and implemented systematically and with co-operative efforts of the members in the Groups.

   Self Help Groups activities should flow like a river finding its own coarse. There is no need to give formal set up to Self Help Groups by giving labels, and designations should be avoided. The principle of equality within the group is the key to organize successful Self Help Groups.

A Core Committee should not be formed but it should evolve as an outcome of selfless efforts of concerned people with commitments, who should consistently and collectively work, to find solutions to the problems of people with Disability.

Some activities which SHG's can take up in a village

1. Working collectively as a group to start self and small group employment agencies.
2. To start Regular Recreation Groups
3. To establish Counseling Centres.
4. Initiate Distant Education, Braille and Talking Libraries, Toy Libraries, Learning materials and other useful equipment.
5. Create an information Centre especially for Government Schemes.
6. Build up Pressure Groups.
7. Promote Trusts of families and members with disability with severely disabled members to find solutions to problems of care and support after their parents' death.

Resources for Self Help Groups / Mutual Support Groups :

1. Voluntary Services of adults with disabilities and families of members with disability.
2. Existing facilities available in the village community such as school building, community building, integrating recreation activities into the existing recreation centres.
3. Government's Schemes for poverty alleviation to assist in Self and group employment's, insurance for Mentally Handicapped Persons, Self Help Group loans to the members.
4. Mobilizing family trades and local employers to generate employment for the Disabled members in the group

Eligibility. All disabled adults above 16 years.

Parents and sibling can become members, if the member of their family with disability has severe mental handicap. People with Mental handicap should be encouraged to participate in all the activities of Self Help Group and importance should be given to the opinions and suggestions that concerns their lives. At least 50% of members should be women. Addresses of DPI's in Bangladesh, Srilanka, Pakistan, Nepal.

1. Mr. Khondoker Jahurul Alam, Chairman, Bangladesh Protibhandhi Kalyan Somity (BPKS), 2/5, Hymensingh Road, Shahbag, Dhaka, Bangladesh, GPO Box No. 3082, Dhaka 1000, Phone : 865502 Fax : 880-2-863307

2. Mendis M.C. House No. J/G/3, Mt. Lavania Flats Kaldemullar, Ratmalana, Srilanka. Phone : (Res) 941 611056 / (Off) 941 431932 Fax : 941 446543

3. Malik Salah, Ud Din, 34, Sadar Bazar Gulam, Mohammadabad, Faislabad, Pakistan Phone : 9241 680439 / 628300 Fax : 9241 617987

4. Ms. Bonnie Rai, C/o. Mr. Govinda Rai, Nepal Association for the Welfare of the Blind, Tripureshowar, Kathmandu, Nepal. Phone : 977 214037 / 215482 Fax : 977-1-226057

Dear CBR Network User

I am please to share guidelines on how to start Self Help Groups of people with Disability. Its approach in Karnataka has worked very well both in Urban and Rural setup. However there is a need and urgency to promote Self Help Groups in CBR programmes in Rural / Tribal areas.

Please feel free to :

Share the material with other Ogranisations

Translate the material into local languages, and send CBR Network a copy

Partnership Market News

Requests received in the months of February '97.

R0001 : Simple screening formats - Raichur IED survey conducted by Govt. of Karnataka.

R0002 : IED and CBR Curriculum integrated in TCH Training in Karnataka.

R0003. : TALC Curriculum to train adults (with disabilities) to live in their own communities.

These requests are received from the Ministry of Welfare Government of India)

R0004 : Distance Braille education programme 6 months curriculum. The above requests was received by NAB, Bombay. All offers and requests were met by CBR NETWORK. Please send your offers and requests to the Partnership Market.

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